DOCUMENT RESUME

ED 470 822 EC 309 276

AUTHOR	Walker, Pam
TITLE	Community Participation and Social Networks: An Information Package.
INSTITUTION	Syracuse Univ., NY. Center on Human Policy.
PUB DATE	2002-05-00
NOTE	69p.
AVAILABLE FROM	Center on Human Policy, Syracuse University, School of Education, 805 S. Crouse Ave., Syracuse, NY 13244-2280. Web site: http://soeweb.syr.edu/ thechp/community_package.html.
PUB TYPE	Collected Works - General (020) -- Reference Materials - Bibliographies (131)
EDRS PRICE	EDRS Price MF01/PC03 Plus Postage.
DESCRIPTORS	Adults; Citizen Participation; *Community Resources; *Developmental Disabilities; Friendship; Interpersonal Relationship; *Social Integration; *Social Networks

ABSTRACT

This information packet presents five readings about community participation and social networks of people with developmental disabilities and an annotated bibliography. The first paper, "Building Stronger Communities for All: Thoughts about Community Participation for People with Developmental Disabilities" (Robert Bogdan and Steven J. Taylor), focuses on what it means for the individual to be a part of the community. The second paper, developed by the Center on Human Policy, is "A Guide to Knowing Your Community," which offers ideas about places, associations, and activities within the community appropriate for people with developmental disabilities that might otherwise be overlooked. The third paper, "Other than Clients: Reflections on Relations between People with Disabilities and Typical People" (Zana Marie Lutfiyya), describes some key aspects of assisting people to form meaningful relationships. The final two readings, "Citizen Participation: Connecting People to Associational Life" (Sharon Gretz) and "Community Building in a Chicago Neighborhood" (Michael Ervin), offers stories, strategies, and reflections related to promoting community participation and social networks. The annotated bibliography lists 38 references, published from 1985 through 2001, with full bibliographic information, publisher addresses, and abstracts. (DB)

Reproductions supplied by EDRS are the best that can be made
from the original document.

ED 470 822

COMMUNITY PARTICIPATION AND SOCIAL NETWORKS: AN INFORMATION PACKAGE

May 2002

Prepared by:

Pam Walker
Center on Human Policy
School of Education
Syracuse University
805 S. Crouse Avenue
Syracuse, NY 13244-2280

CONTENTS:

PREFACE

PART I: SELECTED READINGS

Building Stronger Communities for All: Thoughts About Community Participation for People with Developmental Disabilities
by Robert Bogdan and Steven J. Taylor

A Guide to Knowing Your Community
by the Center on Human Policy

Other Than Clients: Reflections on Relationships Between People with Disabilities and Typical People
by Zana Marie Lutfiyya

Citizen Participation: Connecting People to Associational Life
by Sharon Gretz

"Community Building" in a Chicago Neighborhood
by Michael Ervin

PART II: ANNOTATED BIBLIOGRAPHY

BEST COPY AVAILABLE

EC 309276

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)
✓ This document has been reproduced as received from the person or organization originating it.
☐ Minor changes have been made to improve reproduction quality.
• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

PERMISSION TO REPRODUCE AND DISSEMINATE THIS MATERIAL HAS BEEN GRANTED BY
S. Taylor
TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

PREFACE

This information packet focuses on community participation and social networks. It was previously prepared by Zana Marie Lutfiyya in 1991 as an information package on "Personal Relationships and Social Networks." While many more people with developmental disabilities live in the community, many of them still lack opportunities for participation in community places, activities, organizations, and events and for social relationships with other community members. Such participation and relationships are the key to a sense of community membership and belonging. Traditionally, human service agencies have, in many ways, created barriers to community participation and social relationships. In recent years, however, increasing numbers of agencies are making significant efforts to assist people in meaningful community participation and relationships. This has involved supporting people to engage in social relationships and friendships; to join community organizations and associations; and to take part in neighborhood and community places, events, and activities.

Part I of this package begins with an article by Robert Bogdan and Steven Taylor that discusses critical issues related to community participation for people with developmental disabilities. The second article, "A Guide to Knowing Your Community," offers ideas to assist in thinking about the places, associations, and activities within your community. The guide is not intended to tell you how to connect people with disabilities to the community; it is intended to help you see aspects of the community you might otherwise overlook. Next, "Other Than Clients: Reflections on

Relationships Between People with Disabilities and Typical People" by Zana Marie Lutfiyya describes some key aspects of assisting people to form meaningful relationships. The final two articles, "Citizen Participation: Connecting People to Associational Life" and "'Community Building' in a Chicago Neighborhood," offer a number of stories, strategies, and reflections related to promoting community participation and social networks.

Part II consists of an annotated bibliography of resources related to community participation and social networks.

Preparation of this information package was supported in part by the National Resource Center on Supported Living and Choice, Center on Human Policy, School of Education, Syracuse University, through the U.S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133A990001. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred. I would like to thank Rachael Zubal for her assistance in the preparation of this information package.

SELECTED READINGS

Building Stronger Communities for All: Thoughts About Community Participation for People with Developmental Disabilities

by

Robert Bogdan and Steven J. Taylor

10

Building Stronger Communities for All

Thoughts About Community Participation for Individuals with Developmental Disabilities

Robert Bogdan and Steven J. Taylor

Professionals in the field of developmental disabilities have been trendsetters in talking about *community*, advocating that people with developmental disabilities should not be segregated from society in institutions but instead should be included in the community. The initial conception of *community*, however, was vague—a hazy picture of a place where people lived with one another in harmony, where they had meaningful and satisfying face-to-face relationships, and where they cared about and looked out for each other.

Eventually, other people outside of the developmental disabilities field started to become concerned with community. However, their concerns related to their own lives and their fears that they were losing a sense of community. While we were fighting to get people with developmental disabilities into the community, social critics declared that community was declining in the United States (McKnight, 1980). Rather than people experiencing where they live as a place where people have close face-to-face relationships, know each other, and are neighborly, too much of our society has become a place where people are isolated and estranged from each other. Malls and super stores have replaced more neighborhood-centered institutions, such as the local merchant, the corner store, the butcher, and the baker. Mass media and the Internet have become substitutes for church, civic organizations, community associations, and so forth.

The preparation of this chapter was supported by the Center on Human Policy, School of Education, Syracuse University, through a subcontract with the Research and Training Center on Community Living, University of Minnesota, supported by the U.S. Department of Education, Office of Special Education and Rehabilitative Services (OSERS), National Institute on Disability and Rehabilitation Research (NIDRR), through Contract No. H133B980047. Members of the Center are encouraged to express their opinions; however, these do not necessarily represent the official position of NIDRR and no endorsement should be inferred.

BEST COPY AVAILABLE

How can we think about including people with disabilities in the community when a sense of community has become so problematic for everyone—when the community itself is under siege? It is important to approach the challenge of helping people with disabilities become part of the community with full appreciation of what is at stake. Thinking about community for people with developmental disabilities might help us think about it for ourselves. What we want for them—a sense of belonging to a community—is what we search for for ourselves. To try to solve their problem is to address our own. It is what we share that ties us together. That is our humanity. This is what makes "them" really part of "us."

This chapter presents some thoughts and observations about what it means for people with developmental disabilities to be part of the community.

BEING PART OF THE COMMUNITY

Being *in* a community is not the same as being *part of* a community. Early formulations of community living for people with developmental disabilities were generated out of concern with deinstitutionalization. We wanted individuals with disabilities to leave institutions, but we were not clear enough in distinguishing that they should be *part of* the community. People can live in the community and experience segregation, isolation, and loneliness. Community placement is merely a first step. Being *in* the community points only to physical presence; being *part of* the community means having the opportunity to interact and form relationships with other community members. Today, this is referred to as inclusion.

What Does It Mean to Be Part of the Community?

Being part of the community means having meaningful relationships with community members. To be part of the community is to be a family member, a neighbor, a schoolmate, a friend, a casual acquaintance, a church member, a shopper, a co-worker, and a significant other. It means belonging to clubs, organizations, and associations and sometimes being a consumer of services as well. Being part of the community means much more than being treated nicely by staff or even having a citizen advocate or volunteer. It means being known as an individual, a unique person—not as a label, a ward of the state, a client of an agency, a consumer of services, or the recipient of another's charity.

Early sociological and anthropological studies concentrated on how people with disabilities were stigmatized and excluded from the community (Bogdan & Taylor, 1976; Edgerton, 1967; Goffman, 1963). We now understand the dynamics of labeling, stereotyping, and the self-fulfilling prophecy. Unfortunately, we know far less about how people make friends and how those who are

different come to be accepted. We still need a sociology of acceptance (Bogdan & Taylor, 1987b).

Being part of the community means contributing to the community. It means being a good citizen. Although this usually involves holding a job, it also means contributing in other ways—volunteering, celebrating when the community celebrates, grieving when tragedy strikes, and engaging in neighborly acts. Ties to the community are fragile when they are not based on reciprocity. The inclusion of people with developmental disabilities in a neighborhood should make the community a better place to live.

Being part of the community requires being supported by services and agencies in such a way as to become less dependent on those services and agencies. When individuals with developmental disabilities have to rely exclusively on the services of agencies, they are destined not to become part of the community. The more agencies provide services for these individuals, the less others will be involved in the individuals' lives. Only when support is spread throughout the community can individuals with developmental disabilities be fully included in their communities.

Institutionalization has been defined largely in terms of physical placement in remote facilities, but it can be much more insidious. It also can be described as total consumption of a person's life by an agency or a program. When this happens, the person becomes defined by his or her disability label; the "client" role takes over, and the person becomes lost. When, however, a person has a range of contacts in the community, he or she becomes a "consumer" of services, rather than a client. It is important to define community inclusion not simply in terms of the demise of deinstitutionalization but in terms of breaking down the control that services, programs, and agencies have over the lives of individuals with disabilities. Professionals and staff must view themselves not as people who are all things to their so-called clients, but as community organizers and mobilizers—people who help the people they serve become part of their communities.

Being part of the community should never be confused with neglect, indifference, or denial of support. Although the goal is for people with developmental disabilities to become part of their communities, this cannot be used to excuse the denial of supports and services to these individuals. Being part of a community does not mean that people with developmental disabilities or their families must do without support from publicly funded agencies.

This is a particularly salient issue with individuals with mild cognitive limitations. Because of the current anti-welfare mentality, they are most vulnerable to being abandoned by governmental agencies that search for less inclusive definitions of what constitutes need.

Being part of the community ultimately means doing away with concepts such as normalization, integration, quality of life, and inclusion. These and other concepts are only vehicles for change and not the end result. When a state of

BEST COPY AVAILABLE

full acceptance and inclusion of people with developmental disabilities is reached, these ideas no longer will be necessary. That we have these concepts does not mean that we have arrived; it only means that we recognize that people with developmental disabilities have been denied. In other words, we only examine people's quality of life when we suspect that it is lacking (Taylor, 1994).

Normalization, integration, and inclusion can carry with them a level of self-consciousness that can interfere with people becoming part of the community. Normalization is not normal. Inclusion is not inclusive. When individuals in a community focus on such concepts, they can find it difficult to have spontaneous and natural relationships with people with developmental disabilities. Spontaneity is characteristic of mutual relationships.

We can envision a society that would perplex the most adamant believers in normalization or inclusion. That society would be marked by a natural acceptance of people with disabilities. Members of this society would not have the faintest understanding of normalization principles. If one asked them about inclusion, they would not know how to respond. The society would not operate on normalization; instead, they would operate on spontaneous, natural acceptance. Here the use of concepts such as normalization, quality of life, and inclusion would represent a step backward.

Being part of the community is an end in itself. People with developmental disabilities who are part of their communities act in more typical and socially appropriate ways. They may indeed become more independent and economically productive. However, the strongest argument in favor of enabling people to become part of their communities is that they lead better, more fulfilling lives.

It is important for agencies to operate under the assumption that people can change and learn new skills and that the most difficult behavior problems can be overcome. However, even if people do not change dramatically and become more independent and productive, they still should be able to be part of the community. The right to lead a decent life as part of the community should not be made contingent on becoming "nondisabled" or "normal" (Ferguson & Ferguson, 1986).

Being part of the community cannot be "packaged." Just because an idea, model, or approach seems to work in one place at one time does not mean that it can work anywhere or at any time (Lyle O'Brien, O'Brien, & Mount, 1997). To be sure, we can all learn good ideas from other people, and some models are inherently superior to others. We cannot assume, however, that every good idea can be replicated with equal success. We all know that there is a difference between having a home-cooked meal and eating in a franchise restaurant. What makes the difference is not the recipe but the care, attention, and personal touch that go into the cooking.

Reliance on specific models or approaches can interfere with helping people become part of the community. Just as we have learned not to invest in the

bricks and mortar of institutions, we must not bet on one particular approach to inclusion.

Steadfast adherence to a particular approach can prevent new professionals in the field from having the opportunity to contribute to the creativity and insight required to develop better ways of doing things. As more and more community programs develop, recruitment of staff is becoming more routine; it is no longer like joining a spirited movement as it has been in the past. It is necessary to find ways of helping new professionals develop a sense of the history of the struggles that brought us to where we are today, while at the same time being open to fresh ideas. For people with developmental disabilities to become part of the community, a strong commitment, a sense of mission, and clear values will be necessary (Provencal, 1987; Taylor, Bogdan, & Racino, 1991). None of these things can be packaged.

Being part of the community is not an unrealistic goal. Although the history of the treatment of people with disabilities in the United States is rife with instances of discrimination and exclusion, this is not inevitable. To the contrary, an increasing number of examples of full participation of people with developmental disabilities in the community can be found (Andrews, 1995; Bogdan, 1995; Bogdan & Taylor, 1989; Taylor, Bogdan, & Lutfiyya, 1995). Ironically, some of the richest examples of inclusion have resulted not from professional engineering, but as a consequence of ordinary social processes (Andrews, 1995).

Too often we have expected rejection and exclusion of people with developmental disabilities. When such people are not accepted in neighborhoods or included in community groups, it is viewed as a normal and natural outcome of backward attitudes and prejudice. We need to pay more attention to how our own practices, such as grouping people with developmental disabilities, tend to discourage inclusion; we also need to devote greater attention to identifying the kinds of communities or associations in which people with developmental disabilities will be accepted.

Being part of the community will require a return to communal values. As an understandable reaction to the anonymity and block treatment of people with developmental disabilities in institutions and segregated environments, the field has turned to a set of new concepts that endorse individual autonomy: self-advocacy, self-determination, person-centered planning, homeownership, individualized services, and so forth. Although these concepts can help us move toward a service system that is more respectful of the uniqueness of all people with developmental disabilities, an exclusive focus on individualism will prevent people with developmental disabilities from being part of the community. Community has to do with *we*, not *I*. An emphasis on the individual must be balanced with communal values (O'Brien & Lyle O'Brien, 1996).

Being part of the community means recognizing that people with disabilities are more than mere victims. Despite the fact that people with developmental disabilities and their families have been subjected to prejudice, discrimination,

BEST COPY AVAILABLE

and even abuse, they should not be regarded as passive objects that happily conform to what is expected of them. Although the phenomena known as the "self-fulfilling prophecy" (Wolfensberger, 1972) and the "client role" are real and undoubtedly exercise a strong influence on the way in which individuals and families feel and act, to define people solely as victims is just as dehumanizing as defining them solely as clients of human services. Because they are human beings, people with developmental disabilities and their families sometimes conform to the dictates of the human services system and societal expectations and sometimes do not. Families may reject negative stereotypes and construct positive definitions of their children (Bogdan & Taylor, 1989; O'Connor, 1995). People with developmental disabilities do not always view themselves in terms of their impairments, and they are able to take an active role in controlling their lives (Shoultz, 1995; Taylor, 1994, 2000). One of the most striking aspects of deinstitutionalization is that some individuals with disabilities emerged from the experience as survivors with their dignity and self-respect intact.

When people with developmental disabilities have become part of the community, it has often been at their own initiative. Inclusion was not something done for them by others but something that resulted from their own contributions and characteristics.

Being part of the community will take time. Frustrations and setbacks will occur in helping people with mental retardation and developmental disabilities to become part of the community. Communities may not always welcome people with developmental disabilities with open arms. Relationships may not always form spontaneously. Acceptance and inclusion will not be accomplished overnight.

When people with developmental disabilities are visible and involved in their communities—in schools, workplaces, and neighborhoods—good things happen. If community members do not step forward to take over for agency staff, this should not be cause for despair. Progress toward the goal of inclusion should be measured in terms of kind words and subtle gestures, a greeting on the street, an offer of a ride home, or an invitation to dinner or a party.

Being part of the community will require changes in the society. For people with developmental disabilities to become part of the community, society will have to change. Personal relationships are the cornerstone of being part of the community; however, social policies and practices can systematically thwart opportunities for individuals to come together. Until vested interests, funding mechanisms, economic policies, counter-ideologies, agency policies, architectural barriers, and other forces supporting segregation are confronted and changed, large numbers of people with developmental disabilities will not become part of the community.

One of the major barriers to full community participation for people with developmental disabilities is the economic structure in the United States. Most

adults with developmental disabilities, even those who work, are poor. Poverty severely limits where and how people can live.

The concept of normalization, which was popularized in the United States by Wolfensberger (1972) in the 1970s, had its origins in the Nordic countries. We also can learn from how the Nordic countries approach equality. A central premise in the Nordic countries is that all people have a right to a decent standard of living. Reforms in developmental disabilities have been tied to this idea. It is not that people with developmental disabilities have a right to a decent life because they have disabilities; they have the right because they are citizens.

The link between normalization and equality is clear in the Nordic countries. In the United States, people with disabilities receive government benefits such as Supplemental Security Income (SSI) or Social Security Disability Insurance (SSDI) not because they are citizens entitled to a decent standard of living but because they have disabilities and presumably are unable to work and contribute to the society. Government support is based on presumed differences from other people. Disability becomes central to a person's status as a citizen. Public policy on welfare and equality runs counter to the ideal of inclusion and of being defined as a human being rather than as someone who is different.

CONCLUSION

For people with developmental disabilities to be part of the community, we must have stronger communities with stronger ties among members. Where do we start? "Before you seek to change the world," wrote the late Burton Blatt, "change yourself" (Taylor & Blatt, 1999, p. 165). Small, modest acts of neighborliness can make a difference, or at least that is the hope. Join neighborhood organizations.[1] Lift your head when you walk. Say "hello" to people. Sit outside. Plant flowers. Buy from your local merchants, even if you have to pay a bit more. Share some of what you have. Take children to the park. Fix it even if you did not break it. Have potlucks. Take an older person grocery shopping. Pick up litter. Talk to the mail carrier. Help someone carry something heavy. Start a tradition. Ask a question. Hire people for odd jobs who do not seem to have anything to do. Organize a block party. Bake extra and share. Ask for help when you need it. Open your shades. Share your skills. Turn up the music. Turn down the music. Listen before you react with anger. Mediate a conflict, rather than take sides. Learn from new and uncomfortable angles. Work at listening.

Building stronger community ties is also something that we can try to do in our professional lives. Avoid gratuitous put-downs of people who are not as sophisticated as you are. Treat ideological opponents with respect, simply be-

[1]The following points are inspired by the poster, "How To Build Community," designed by Karen Kerney and published by The Syracuse Cultural Workers.

cause all human beings are valuable. Take the time to answer questions from a student or a colleague. Acknowledge others' contributions to your own accomplishments. Go out of your way to introduce your staff or students to important visitors.

Understand that by making communities stronger for people with developmental disabilities, you just might make life better for yourself. As Blatt concluded, "The individual's life is irrevocably bound to the welfare of the masses, and only good people can save us and, thus, themselves" (Taylor & Blatt, 1999, p. 167).

REFERENCES

Andrews, S.S. (1995). Life in Mendocino: A young man with Down syndrome in a small town in Northern California. In S.J. Taylor, R. Bogdan, & Z.M. Lutfiyya (Eds.), *The variety of community experience: Qualitative studies of family and community life* (pp. 101–116). Baltimore: Paul H. Brookes Publishing Co.

Bogdan, R. (1995). Singing for an inclusive society: The community choir. In S.J. Taylor, R. Bogdan, & Z.M. Lutfiyya (Eds.), *The variety of community experience: Qualitative studies of family and community life* (pp. 141–154). Baltimore: Paul H. Brookes Publishing Co.

Bogdan, R., & Taylor, S.J. (1976). The judged, not the judges: An insider's view of mental retardation. *American Psychologist, 31*(1), 47–52.

Bogdan, R., & Taylor, S.J. (1987a). Conclusion: The next wave. In S.J. Taylor, D. Biklen, & J. Knoll (Eds.), *Community integration for people with severe disabilities* (pp. 209–213). New York: Teachers College Press.

Bogdan, R., & Taylor, S.J. (1987b). Toward a sociology of acceptance: The other side of the study of deviance. *Social Policy, 18*(2), 34–39.

Bogdan, R., & Taylor, S.J. (1989). Relationships with severely disabled people: The social construction of humanness. *Social Problems, 36*(2), 135–148.

Edgerton, R.B. (1967). *The cloak of competence: Stigma in the lives of the mentally retarded.* Berkeley: University of California Press.

Ferguson, D.L., & Ferguson, P.M. (1986). The new victors: A progressive policy analysis of work reform for people with very severe handicaps. *Mental Retardation, 24*(6), 331–338.

Goffman, E. (1963). *Stigma: Notes on the management of spoiled identity.* Englewood Cliffs, NJ: Prentice-Hall.

Lyle O'Brien, C., O'Brien, J., & Mount, B. (1997, December). Person-centered planning has arrived...or has it? [Perspectives]. *Mental Retardation, 35*(6), 480–484.

McKnight, J. (1980, Fall). A nation of clients? *Public Welfare,* 15–19.

O'Brien, J., & Lyle O'Brien, C. (1996). *Members of each other: Building community in company with people with developmental disabilities.* Toronto: Inclusion Press.

O'Connor, S. (1995). "We're all one family": The positive construction of people with disabilities by family members. In S.J. Taylor, R. Bogdan, & Z.M. Lutfiyya (Eds.), *The variety of community experience: Qualitative studies of family and community life* (pp. 67–77). Baltimore: Paul H. Brookes Publishing Co.

Provencal, G. (1987). Culturing commitment. In S.J. Taylor, D. Biklen, & J. Knoll (Eds.), *Community integration for people with severe disabilities* (pp. 67–84). New York: Teachers College Press.

BEST COPY AVAILABLE

Shoultz, B. (1995). "But they need me!": The story of Anna London. In S.J. Taylor, R. Bogdan, & Z.M. Lutfiyya (Eds.), *The variety of community experience: Qualitative studies of family and community life* (pp. 9–22). Baltimore: Paul H. Brookes Publishing Co.

Taylor, S.J. (1994). In support of research on quality of life, but against QOL. In D. Goode (Ed.), *Quality of life for persons with disabilities: International perspectives and issues* (pp. 260–265). Cambridge, MA: Brookline Books.

Taylor, S.J. (2000). "You're not a retard, you're just wise": Disability, social identity, and family networks. *Journal of Contemporary Ethnography, 29*(1), 58–92.

Taylor, S.J., & Blatt, S. (Eds.). (1999). *In search of the promised land: The collected papers of Burton Blatt*. Washington, DC: American Association on Mental Retardation.

Taylor, S.J., Bogdan, R., & Lutfiyya, Z.M. (Eds.). (1995). *The variety of community experience: Qualitative studies of family and community life*. Baltimore: Paul H. Brookes Publishing Co.

Taylor, S.J., Bogdan, R., & Racino, J.A. (Eds.). (1991). *Life in the community: Case studies of organizations supporting people with disabilities*. Baltimore: Paul H. Brookes Publishing Co.

Wolfensberger, W. (1972). *The principle of normalization in human services*. Toronto: National Institute on Mental Retardation.

BEST COPY AVAILABLE

A Guide to Knowing Your Community
by
the Center on Human Policy

CTAT Field Report
Winter 1990
Vol. 1, No. 1
pp. 8-9.

Every Neighborhood has a network of social Relationships

A GUIDE TO KNOWING YOUR COMMUNITY

Center on Human Policy
Syracuse University

While most of us would agree that people with disabilities should be "integrated into the community," we do not have a clear understanding of what "community" means. Too often, the term "community" is associated with non-institutional facilities and human service agencies. How often have you heard that people are "in the community," when, in fact, they are lonely and cut off from other people?

The purpose of this guide is to help you increase your understanding of what community means and, specifically, to help you look at your own community--the places, associations, and activities in which community members participate. This guide is not intended to tell you how to connect people with disabilities to the community. In fact, we do not believe that connecting people to the community is a simple step-by-step matter. The guide is intended to help you see aspects of the community--hidden resources--you might otherwise overlook. Our assumption is that the better you know your community, the easier it will be to help someone become involved in that community.

There are four groundrules for using this guide. First, *look beyond the "human service community,"* facilities and agencies serving disabled or devalued groups. For the purposes of this guide, these do not count as community. Second, put people with disabilities out of your mind when you use this guide. People often get stuck when they attempt to look at the community with disabilities in mind. One tendency is to think up all of the reasons why someone could not participate somewhere rather than trying to understand a setting or activity in the first place. Third, this guide works best when you use it to look at your own community. The more involved you are in your community, the easier it will be to use the guide. Finally, *use this guide as a starting point for knowing your community.* Try to come up with your own strategies and approaches.

KNOWING YOUR COMMUNITY
Neighborhoods

Neighborhoods, or geographical communities, vary tremendously from each other. Some are tightly-knit and have a strong "we-feeling." People living there know or at least know of each other and share things in common. Others, of course, are more anonymous and may even be characterized by conflict. Yet every neighborhood has a network of social relationships.

1. Select a specific neighborhood or community.
2. Identify the approximate boundaries. Use a map or draw one.
Note: Some neighborhoods have a clear identity and boundaries, while others do not. A long-time resident of a neighborhood may be able to help you draw the boundaries.
3. Take a driving or walking tour of the neighborhood. Identify the "places" in the neighborhood: the variation in housing, stores, restaurants, bars, schools, libraries, parks, laundromats, organizations, churches, and/or synagogues.
4. Observe the neighborhood at different times of the day (for example, early morning, after-school, early evening), weekdays and weekends, and (over time of course) different times of the year.
5. Talk to some long-time members of the neighborhood. Ask them about the places: who spends time where and what do they do?
6. Draw a "social map" of the neighborhood (a map indicating places and people).
What goes on where?
Who uses what places? When?
7. Visit different places in the neighborhood.
How do people interact with one another (if at all)?
What do people do?
Do people seem to know each other? (Does the shopkeeper know the shoppers?)
8. Talk to some people in the neighborhood, both newcomers and long-time residents. Ask them whom they know in the neighborhood and how they met them. Ask them about groups and associations in the neighborhood they are involved with.

Organizations and Associations

Every community has a large number of groups, organizations, and associations, some are formal, with strict criteria for membership. Others are informal and loosely organized.

1. Find an almanac and skim the section on societies and/or associations (most almanacs list major national groups).
Which might be active in your community?
Do they seem to have strict or loose criteria for membership?
2. Select one or a few schools, community colleges, churches, libraries, and organizations like the YMCA, YWCA, YMHA, and YWHA. Find out about groups sponsored by these organizations (for example, many schools sponsor adult recreational groups; churches usually sponsor many activities and groups).
3. Skim at least a week's worth of your community's newspaper, especially local sections, for information on local associations.
4. Talk to a range of people, including young people and older people, long-term residents and newcomers, about the groups and associations to which they belong.

BEST COPY AVAILABLE

Continued from page 8

Ask about (for example):
- Church groups
- Political groups
- Art clubs
- Musical groups (choirs)
- Woman's centers and groups
- Unions or work societies
- Sports teams and leagues (e.g., softball, bowling)
- Collector's groups
- Community associations
- Youth groups
- Film societies
- Membership at recreational centers

Find out about membership in these groups:
- What are the criteria for membership?
- How does someone join?

Ask what the groups are like:
- Who are the key members of the groups (formal or informal leaders)?
- How do different people participate in the groups?
- Are the groups tightly-knit or do members come and go?

Activities

Every community has a nearly limitless range of activities. While it would not be worthwhile to try to identify all of the activities people are involved in any community, find out about recurring activities in which people meet and get to know each other. Many of these will be associated with neighborhood activities or specific organizations and associations.

1. Look for activities in your neighborhood or community paper. Examples include pancake breakfasts and barbeques sponsored by local civic organizations, volunteer fire departments, and churches. Visit some of these. Do people seem to know each other?
2. Talk to a number of people--for example, friends, acquaintances, coworkers--about how they spend their free time. Where do they go and with whom? Ask them about activities in which they know other people.
3. Talk to a number of newcomers and long-term residents of a community about where they buy gas, go out to eat or for coffee, grocery shop for other things. Ask them about places where they are recognized by the owners or proprietors or other customers.

CONCLUSION

After you have completed this guide, you can begin to think about how people with disabilities can become part of neighborhoods, organizations and associations, and community activities. Think in terms of specific people and look for places, associations, and activities in which people know each other. Finally, keep in mind that becoming part of the community takes time.

The preparation of this guide was supported through a subcontract with the University of Minnesota for the Research and Training Center on Community Living, which is funded through a cooperative agreement (Number H133B80048) with the National Institute on Disability and Rehabilitation Research (NIDRR).

Every community has a nearly limitless range of activities.

BEST COPY AVAILABLE

Other Than Clients: Reflections on Relationships Between People with Disabilities and Typical People

by

Zana Marie Lutfiyya

CENTER ON HUMAN POLICY

Other than clients: reflections on relationships between people with disabilities and typical people

by Zana Marie Lutfiyya, Center on Human Policy

Basically, we should look at how we live, different relationships we have, the choices we make...and aim to ensure that our friends with handicaps have the same sort of fulfilling lives we have. **Nicola Schaefer**

Common experiences of people with disabilities

It seems trite to assert that people with disabilities possess the desire and need for relationships with other human beings. Don't we all? Yet at a recent training session with the staff from a residential program, the lack of relationships in the lives of people with disabilities was clearly pointed out. Thinking of the people they worked with, the staff determined that none had "best friends." A few could claim one or two "close friends" while two enjoyed warm ties with their families. All had half a dozen or so "acquaintances" with whom they maintained casual contact. The majority of the people the residents knew were staff, other residents and the people with whom they conducted the daily business of their lives: doctors, dentists, shopkeepers and so on.

Most human service programs (schools, residences, workshops, recreation programs) effectively set up barriers between people with disabilities and most people in their community. Surrounded by paid staff and others receiving the same services, people with disabilities are made into "clients," "service users," or "program participants." Family connections may be ignored or broken. Friends may be discouraged from keeping in touch. A person's history can be lost merely by entering a residential program. Such occurrences are not infrequent. They take place so often that they form a pattern—the "normal" existence for people with disabilities.

It does not have to be this way. Some people with disabilities are well-loved, treated with respect and encouraged to remain connected with their families, typical peers and people they have known in the past.

BEST COPY AVAILABLE

Developing and maintaining relationships

It appears that at least six characteristics, experienced by typical people in their efforts to meet others and develop relationships, may not be as available for people with disabilities. These qualities of our relationships include opportunity, diversity, continuity, relationships that are freely chosen and given, and intimacy.

Opportunity

Typical people can take advantage of numerous opportunities to meet and get to know other people. They meet others through families; neighbors; school/work; cultural, civic and recreational events; church or synagogue. We also come into contact with innumerable individuals simply in conducting our daily affairs: buying food, getting the car fixed, taking care of our health needs, haircuts, etc. In our western culture, it requires effort to avoid meeting new people.

For many people with disabilities, such opportunities are simply lacking, and they possess extremely limited opportunities to take part in activities and events where they can meet their typical peers. And even when people with disabilities may be physically present in a community, a variety of circumstances conspire to keep them apart from their neighbors. For example, program rules and restrictions, transportation, poverty.

Support

Providing adequate opportunities for people with disabilities to meet and interact with valued citizens in positive ways must be the first step toward the building of meaningful relationships. Hand in hand with these opportunities must be adequate support for both the person with disabilities and the typical people involved.

One woman wanted to go to church, something she had not done since she was a child. A church of the right denomination was located, the priest contacted, and a parishioner agreed to sit with Helen during Mass and accompany her to the coffee hour afterwards. For Helen, this effort was not enough. She did not know how to behave in church and smoked cigarettes, talked and swore during the service. Not surprisingly, the parishioner became uncomfortable sitting next to Helen and soon stopped coming to pick her up. Helen needed to be with someone who could guide her appropriately while in church—someone who might suggest going out for a smoke, or sitting quietly until the service ended. Initially, a staff person sensitive both to Helen's need to attend church and the need for appropriate behavior might have made the difference by minimizing disruptions while allowing Helen to attend church and meet others in the congregation. This staff person could then encourage a member of the congregation to support Helen, in the hope that a friendship would develop. Enhancing relationships between people with disabilities and typical citizens is not accomplished by throwing unsupported individuals together with unprepared companions.

On the other hand, support, instruction and guidance must never be confused with the restriction of a person's opportunities to meet and form ties with other people. Human service programs have historically controlled and limited the opportunities available to individuals with disabilities.

Diversity

Ten people at a party were given a unique challenge: Someone suggested that each person attending would know someone who came from, or had been to, virtually any country in the world. The first challenger claimed that no one would know anyone from Borneo, but a woman responded that her secretary was born there. A coincidence? Perhaps. But if we stop to think about it, most of us know a wide range of people with different backgrounds, interests, jobs, education, etc. Although we may not choose to associate with, or become close to everyone we meet, we have the opportunity to select our friends from a large number of different people.

Unfortunately, the same cannot be said of many people with disabilities, especially those who were raised apart from their families and neighborhoods. People served in both institutional and community-based settings may experience little contact with people outside their immediate environment. Along with increased opportunities for people with disabilities to meet typical citizens, must come the support needed to get to know a variety of individuals.

As we introduce people with disabilities to more people, we must also give up some of our control over their lives. The excessive control that human service staff now exercise over the people they serve would be socially inappropriate in the types of relationships that we wish to encourage. We must constantly pay attention to the differences between adequate support, guidance and protection, versus over-protection that unnecessarily restricts a person in his or her movements and associations.

Continuity

Many of us thrive on opportunities to meet new and interesting people. But as we continue to meet new people, we are sustained by those we have known for a long time. The continuity we experience in some of our relationships over the years is an important source of security, comfort and self-worth. Human beings learn to trust each other within long-term, stable relationships.

Many people with disabilities do not enjoy the same continuity in their relationships. Children may leave their families for foster care or residential education programs. Staff people, social workers and case managers can come and go frequently, causing disruption in a person's life. Wolfensberger (personal communication, mid 1970s) likens many people's experiences to a "relationship circus" where staff and professionals dance in and out of a person's life, each in turn demanding instantaneous trust from the person with disabilities. An observer in a supported apartment program learned that her five months' observation gave her some seniority over most of the support staff.

The service providers who surround people with disabilities must learn to support, not to stand in the way of, long-standing relationships of the people they serve. Assisting people to stay in touch is essential. Letters may need to be written and read, phone numbers dialed, transportation provided. Helping a person to remember birthdays, anniversaries and other important occasions are ways to maintain ties. Some people may need help to remember and cherish the history of their connections with others. Some individuals many need assistance during a visit or social event with a friend or relative, such as how to be a gracious host (or guest), carry on a conversation or observe other social graces.

Freely given and chosen relationships

Others like us and love us because they want to. Our spouses, lovers and friends all choose to be with us and we choose them. We are surrounded by people who accept, love and tolerate us and we do the same for them. When this is not the case, we think that something must be wrong somewhere and seek to rectify the situation. Popular culture and our books of wisdom assert that this is as it should be.

Many people with disabilities enjoy few close relationships with others, and even fewer unpaid relationships. The main source of relationships for many people with disabilities are their families, program staff and others in their situation. Given the lack of opportunity and support to meet people in the community, this should not surprise us.

Too many human service program practices prevent freely-given relationships from developing. These practices may include requiring someone to become an official agency volunteer, attending a training course before meeting the people they serve, restricting visiting times and placing the typical people in positions of control. When freely-given relationships do occur, human service agencies often deny the importance of these relationships. A young woman named Judy met Rose, a three-year-old girl living in a children's rehabilitation hospital. Abandoned at birth, Rose lived with several debilitating physical conditions making some movement and handling painful. Judy visited Rose, read her stories, sang songs, rocked her to sleep. One week when Judy came to visit, she found another child in Rose's bed. Rose had died a few days earlier. When Judy asked why she had not been contacted, and why no memorial service was planned, she was offered grief counseling. The staff also expressed surprise over Judy's attachment to Rose.

Some paid relationships *are* characterized by genuine warmth, caring and even love. But it is essential to recognize these qualities in our relationships and their absence from the lives of many people with disabilities. Our goal must not simply be to introduce people to others, but to create the environment that will encourage typical members of our communities to voluntarily choose to form relationships with people whose lives have been marked by separation and loss. Human service staff hoping to support friendships between people with disabilities and typical community members can be direct in their efforts. They can ask themselves, "Who seems to be interested in this person?"; "Who likes this person?" and "Who wants to spend time with this person?"

Intimacy

With its many meanings, the word intimacy may be confusing. It is used here as an expression of the closeness, comfort and trust that people may feel for each other. Intimates can express thoughts and feelings that they share with no one else. Despite the difficulties in determining how a person defines those she or he is "closest to," most people have (or aspire to) a few "intimates."

We are just beginning to recognize that many individuals with disabilities have no one with whom they share a close, intimate relationship. Some may claim such a connection with another, and find this closeness is not shared by the other person. It would be easy to interpret this "fantasy" as a result of the person's cognitive impairments. But if at least one intimate connection with another human being is vital for each of us, this "fantasy" may be necessary for the individual's functioning. There is no easy answer for those who want to support intimate relationships between people with disabilities and their typical peers. All humans struggle in their search for intimate connections with other people.

BEST COPY AVAILABLE

Conclusion

A mark of real acceptance of individuals with disabilities in our communities can be found in the relationships they enjoy with typical people. Although it may be difficult to create such relationships, the opportunities for people with disabilities to meet and interact with those without can be increased and encouraged. The fact remains that human services workers face the dilemma that they *themselves* may be barriers to the development of these desired relationships.

References

Bogdan, R. & Taylor, S. J. (1987). The sociology of acceptance. *Social policy*, Fall 1987.

O'Brien, J. (1987). A guide to lifestyle planning. In B. Wilcox & G. T. Bellamy, *A comprehensive guide to the activities catalog*. Baltimore, MD: Paul H. Brookes Publishing Company.

Wolfensberger, W. & Zauha, H. (eds.). (1973). *Citizen advocacy and protective services for the impaired and handicapped*. Toronto: National Institute on Mental Retardation.

This article was prepared by the Research and Training Center on Community Integration, Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University, with support from the U.S. Department of Education, Offices of Special Education and Rehabilitation Services, National Institute on Disability and Rehabilitation Research, through Cooperative Agreement No. G0085C03503. No endorsement by the U.S. Department of Education of the opinions expressed herein should be inferred.

BEST COPY AVAILABLE

Citizen Participation:
Connecting People to Associational Life

by

Sharon Gretz

CHAPTER 2

Citizen Participation: Connecting People to Associational Life

Sharon Gretz

Not too far from Pittsburgh, there is a tiny little town with a funny name which no one ever seems to have heard of. The heart of the town, on the main street, is a delicatessen. At the deli, a steady trickle of townspeople come in in the morning and again at lunch for fresh-brewed coffee, enticing food and friendly conversation. Several years back I found myself there. This little town with the funny name held a special interest for me. Soon the deli would hold a special significance as well.

Stunned and knocked to its knees in the early '80s by the collapse of the steel and manufacturing industries, the town was now fighting to come back. Recovery and rebirth were in progress. However, many people were forced to leave to find work and provide for their families. Those who remained in the community were put in the position of needing to pull together if there were going to be any community at all.

In the midst of this process, eight new people had moved into town. These individuals had no ties to the community whatsoever. They had no roots, no history there. In fact, community, any community, was hardly contained in their histories at all. The eight people had severe disabilities. Between them, their histories held over 145 years of life within the walls of institutions.

In 1985 the agency for which I worked led a complex effort to "spring" these eight people from institutions to life in a community. The community picked was the little town with the funny name.

December 23rd, 1985 was liberation day. The whole thing took a tremendous amount of energy, persistence, and probably audacity. Oh, it was a great feeling to see them leave. Exhilarating, in fact — for the people who moved and for the people who played a part in making it happen. One of the public entities that had made it possible was the state Developmental Disabilities Planning Council. They had initiated a project to get people with disabilities out of nursing homes. They had provided money for people to set up their households.

Sharon Gretz has worked in human services for people with severe disabilities since 1979. In her citizen life she is a cub scout den mother, on the board of a parent-teacher organization, and a citizen advisor to her local school board.

BEST COPY AVAILABLE

After several years it was clear that those who had believed that these eight people were not capable of living in the community had been wrong. They were still there. They were making it. They had staff support. They were involved in day training programs to learn skills. There were staff available to attend to their personal care needs. There were staff to take them shopping, banking and out to dinner. Yet something began to gnaw at those of us at my agency who were intimately involved in this whole thing. The feeling was inarticulate at first, but the gnawing arose with the question "Is just being there enough?" Was life in the community about simply being present, or did it have to do with having a presence? Tom Kohler, who is involved in citizen advocacy in Georgia, cut through everything. For me he posed the question, "If you imagined two worlds, the client world and the citizen's world, where would you say most people spend the bulk of their time?" I remember feeling like my heart stopped. There was no need to think about the answer. Our people were clients all of the time. In this little town where they lived, the people I knew, the liberated eight, were virtually invisible. Although they were there, they were not seen and certainly not known. Few, if any, relationships had developed outside of "the program." Belonging had not come by simply being there.

With this reality in our minds, we again looked for a way to help these eight people "live in the community." We wanted to find ways of helping people belong — to be full-fledged citizens.

About this time the state Developmental Disabilities Planning Council made funding available for a new kind of project called "Citizen Participation." We wrote a proposal, and were awarded a grant. It was just a small grant in terms of money. With this tiny little grant we began. I was hired to figure out what this new approach would be. As it turned out, I didn't know what I was getting myself into. I was used to things like developing policies, designing programs, making assessments, writing reports, supervising staff, counting units of service, coming up with "forms" for this or that, and generally "putting out fires." With this, I couldn't just call someone else in my field and ask for the "how-to's." At the time, I knew no one in my professional world who was doing this kind of work. And so this tiny little town and this small grant held a certain intimidation for me. My own struggle began with the question, "How can I get in touch with the real life of the community?"

We started with the idea of finding a community member who would be a "bridge builder" between the eight people we supported in apartments and the town itself. The "bridge builder" would need to be someone who was well known and respected in the community,

who belonged to many associations and groups, and who was innocent of involvement in our human service world.

When the time came to look for our first "bridge builder," I started to become uncomfortable and actually afraid about how to do it. I guess in my mind I knew that putting an ad in the Sunday classified would not do it. But what would? I started by asking people from work if they knew anybody who might know someone else who was very involved in the community. After a few tries, someone told me that his aunt had lived there all of her life and maybe she could help. He called his aunt and she said that the person we should talk to was Sophie.

I found out that Sophie was a hairdresser who had run a shop in town for many years. She was also the mayor. Would she be well known? If you think about a small-town beauty shop, chances were high she would know just about everybody and everything in town. Would she be well-respected? Well, after all, someone had elected her mayor and trusted her enough to be the top-ranking leader of the community. And finally, she had no ties to the human service world. Perhaps she could help. I needed to call her and ask.

I was given Sophie's telephone number. I want to be perfectly honest here and tell you that I looked at Sophie's telephone number on my bulletin board for many days. As I struggle now to understand my hesitancy to call her, several things come to mind. How could I ask a perfect stranger to get involved? What if she just said no? Would her "attitude" be right? Finally I called.

I went to meet Sophie one day to get to know her. We met at her office as mayor because it was Monday. On Mondays, Wednesdays and Thursdays, Sophie works as mayor. On Tuesdays, Fridays and Saturdays, she cuts hair at the beauty shop. As we began to talk, Sophie's phone rang constantly. No, she hadn't heard about any jobs lately; yes, the town council would meet Monday night; etc. During some of her phone calls I started wondering what I would say. I didn't want to interview her. How would I know if she was the one?

I can't remember now exactly what I said but somehow I told her why I was there. Sophie immediately started to tell a story about a woman she knew who had cerebral palsy and went to live in an institution. Some years later the woman wanted to move out of the institution and back to an apartment high-rise in her town. She kept calling Sophie and asking her to help her come home. Eventually, Sophie was able to help arrange it. Sophie said everyone in the building was nervous and upset when it came time for the woman to move in. Sophie thought that was silly and made it her business to talk to everyone in the building about her friend's abilities, nice personal-

BEST COPY AVAILABLE

ity, and desire to come back home. When her friend finally moved in, the people in the building had a welcoming party.

Sophie went on to tell me about some other people with handicaps who had moved into a new special "independent living" building in town. She was worried they might become isolated. So she had invited them to come to a tea party on community day and had made special arrangements so they could get into the building. No one came. She didn't understand why they didn't come. She thought maybe I knew why. Sophie wanted to know if she did something wrong.

Sophie went on to say that if we were going to be working at getting people involved in the community we needed to talk to Frank. She said Frank knew everybody in a thirty-mile radius and belonged to every association, group, and club. In fact, Frank had probably started most of them. I made arrangements to come back again to meet Frank. On the way out, Sophie asked me again if she had done something wrong when the new people in the special building didn't come to the tea. As I looked into her questioning face I felt compelled to supply an answer. As I searched my mind looking for words or theories to provide some type of professional explanation, I realized that there were none — none that could or should negate her kind and open gesture. I just quietly said no.

I went back to Sophie's office on a later day to meet Frank. Frank is technically retired from work in a local factory. His handshake and smile are warm and welcoming. We all decided to walk to the deli down the street to have coffee and talk. As we walked I noticed how different my pace was from theirs. Frank and Sophie slowly sauntered; Frank with his hands loosely in his pockets, Sophie casually swinging her purse. Me — I was fighting to slow my typical fast and long strides, carrying my purse and my overloaded briefcase.

As we walked I felt in good company. Everyone we passed said hello to Sophie and Frank — a lady carrying shopping bags; people driving by; men gathered on a bench on the corner outside the post office. In the deli, everyone who worked there knew them too. A small group of people were gathered just inside the door. Some were young and some were old. All had a kind word and a comment on the day. I was introduced to all of them. Sophie sold some raffle tickets as we waited for coffee.

Sophie and I talked with Frank about what we wanted to do about getting people whom I supported in their apartments more involved in community life. Frank said he thought it was a good idea, but didn't want to commit himself right that minute. He said he had so many activities that he didn't want to say he could help until he had thought about it. Frank pulled out a folded piece of paper from his breast

BEST COPY AVAILABLE

pocket and showed it to me. On the paper were notes of meetings and times — Lions Club, Festival Committee, Food Pantry and so on. I thought it was interesting that he didn't have an appointment book.

Frank started to tell me a story about when he ran a band group of kids that marched in area parades. Frank is very involved in parades. A girl who couldn't use her right arm wanted to be on the flag team. Some parents of other kids began to complain because she was the only one who carried a flag in her left hand and it messed up the flag formation. The parents said the group wouldn't be judged well in parades. Frank told them he didn't care; the girl was marching and she would carry her flag in her left hand. He said the girl is about thirty now and when they run into each other in town he feels good because she always talks about the band group, and how happy she was carrying the flag. Something inside me felt good, too. Then Frank said he didn't care who a person was, what problems they had, or what people couldn't do. What was important was, if someone wanted to be included then there was something important that he could find for them to do. Frank told Sophie he could help if we wanted him to.

Meeting Frank and Sophie and spending time with them sensitized me in an unexpected way, as a person as well as a human service worker. They taught me in small ways, never intending to change me as I may have initially meant to change them. Although I didn't realize it at first, I came to them expecting that I would be the teacher, the educator, the expert who would instill in them and their community how to go about "community integration." While I was busy explaining about people's physical limitations, they were already brainstorming about what people could do. I sensed in Sophie and Frank this enormous capacity for caring. It didn't have anything to do with "disability." It had to do with how they felt about all people. They sensed utility and worth in everyone. They wanted their community to be a good place to live. Over the years they had been willing to invest in making it that way.

I initially worried because Sophie and Frank didn't know about word usage and terms I used. "Social Role Valorization," goal plans and units of service meant nothing to them. Someone at my agency asked me if they were really qualified to do what we wanted them to do. I labored over that thought for a great while. Eventually I came to just know that their "professional" qualifications were not an issue. The only way I can describe having come to this conclusion is that my heart told me. Inviting people into community life was already their life's passion. They had shown me their capacity to welcome and embrace people. I didn't worry any longer about what words they knew. And finally when I went to the deli to talk and have coffee with

BEST COPY AVAILABLE

Sophie and Frank, I no longer carried my briefcase. Once we agreed upon what we wanted to do together, we arranged for Frank to receive a small "retainer" to help defray some of his expenses. The first person he started to connect with the community was Albert.

Albert

Albert is a rather heavyset man in his early sixties who spent the bulk of his years living in a nursing home. Albert is a tremendously likable guy who talks and laughs loudly. He frequently dons a strawbrimmed hat and wears suspenders and large boots that are seen by some as his trademark. Albert's labels include cerebral palsy and mental retardation. He uses a wheelchair to get around. It almost always takes him a long time to complete a thought out loud as he stutters quite severely. Albert is also quite notorious for being as stubborn as a mule.

Frank arranged for Albert to help out once a week at a local free food pantry for the many unemployed people in town. Frank organized, started and runs the food pantry. Each week Albert joins the other volunteers who give out food. Albert is responsible for handing out tickets to families as they come in. Each ticket is numbered. But since Albert didn't know his numbers, they had to figure out a way to keep them in order. Since Albert started at the food pantry they tried several systems so that he could do his part. Frank and another person also began helping Albert learn numbers in quiet moments at the pantry. Frank told me that Albert has come to recognize more and more of the numbers. The funny thing is that it never happened in ten years of instruction at special day programs.

The people at the food pantry really like Albert. Frank says they kid and joke with him all the time and help him out when he needs it. Albert, originally rather subdued, has warmed up to them as well. Even the families who come in look forward to seeing him there.

When Albert lived in the nursing home, he got in the habit of securing his most prized possessions by wrapping them in many layers of handkerchiefs, socks and bags and keeping them close to his body. Each week at the food pantry, someone asks Albert if he'd like to put on his name badge, at which time he gets out one of his bags and proceeds to unwrap the many layers to reveal his prized badge. In social service circles this is known as "institutional behavior" that needs to be corrected. At the pantry this is just known as Albert's ritual. One of the workers there told me that the ritual means that Albert feels proud to be a part of their group. It never occurred to them that there was anything wrong with it.

It's important to understand that everything has not been perfect either. I remember the time after Albert had been at the pantry several

BEST COPY AVAILABLE

months when Frank called me to say that there was a problem. Albert wasn't making it to the bathroom in time and was wetting himself. My reaction was one of horror and fear; fear that they were going to suggest he not come anymore. Sure that I was going to beat Frank to the punch, I suggested perhaps someone else could or should take Albert's place. Frank was shocked. "Absolutely not!" he replied. Albert belonged with them. They just wanted to solve the problem. As it turned out, arrangements were made for Albert's attendant to meet him at the food pantry and help him get to the bathroom. When things are quieter, Frank helps him, too.

Sometimes Albert dozes off and someone slips by without their ticket, which messes up the system. Frank comes by and pokes Albert when this happens. Now he has a sign at Albert's table that says, "Please stop here and get a ticket." Sometimes Albert would mix up the tickets and give out the wrong ones. They fixed that by making a stick post and putting the tickets on it. Albert just has to pick the one on top. Occasionally there are people who don't want to deal with Albert. When this happens, Frank's response is "If you want food, you have to see the man."

Two years have passed and Albert is still there. Everyone associated with the food pantry has accepted Albert just as he is. I'm sure many professionally experienced persons would look at Albert's deficits and deem him unready. At the food pantry Albert's disabilities aren't denied, yet his unique contribution is accepted and welcomed. Nobody tries to change him. He has a place.

Pete

Pete is a gregarious guy in his fifties. Pete gets immense satisfaction in telling off-color jokes to unsuspecting parties. His laugh afterwards is probably the most infectious I've ever heard. Pete also is devoted to his faith. He loves to read the Bible, talk about Scriptures, and talk about God's presence in his life. Pete fell off a truck when he was a young man. His fall resulted in serious head injury. Pete lived at home with his mom until she could no longer take care of him. He spent many years in a nursing home before moving to his own apartment two years ago. Sometimes Pete gets very agitated, aggressive, and hard to reckon with.

I asked Frank if he might get to know Pete and his interests, and Frank decided to take him along to his weekly community Bible study group. The first week people listened silently as Pete told his story and shared his faith. I am told that Pete's presence is appreciated and his remarks respected within the group. Never at a loss for words, Pete at times monopolizes the conversation and interrupts people who are

BEST COPY AVAILABLE

talking. From what I understand, people in the group handle this by lightly squeezing Pete's arm when he starts to take over. Pete has come to understand that in this group when that happens he needs to give someone else a turn.

Frank told me after one Bible study meeting, Pete blew up at a man when he suggested to Pete that it was cold and he might want to put his coat on before he left. That old apprehension still dwelled in me somewhere. I asked Frank what he told the man. Frank told him "Pete doesn't mean anything bad by it. He just does that once in a while." They still wanted Pete to come. I was also surprised to find out sometime after the fact that the people in the Bible study built a ramp for Pete so that he could enter the church with more ease.

Sometime after Pete had become a regular member of the Bible study his day program came to a halt. The agency that had been funding his program had decided he was not capable of working, so they gave up trying to prepare him. Now Pete had absolutely nothing to do with his days. He came down to our agency building and tried to help out but usually ended up just sitting around. By this time I had met Gene, who was a good friend of Frank's. Gene was a helper at the food pantry and had taken a liking to Albert. Gene told Frank and me that he wanted to get involved in helping our citizen participation efforts. Gene was a lifelong resident who had been an executive in the sales field. When I met Gene he was between jobs and had pretty much given up on wanting to be a part of the sales field any more. He was looking for something different in his life — a way to be of real help to the people in his community. This was what led him to the food pantry, and Frank in particular. As he expressed it to me, he saw in Frank what lived and breathed in his own heart. Frank was a symbol of pure love—an example of how human beings could interact in their world. He started spending time with Frank and learning from him.

Gene already knew Pete. I asked Gene if he thought there might be something for Pete to do in the community that would have some real meaning. Gene contacted his friend named Lynn Ann. Lynn Ann had several years earlier begun, as she put it, "to try and get neighbors helping neighbors. There were many problems facing our community." Her network grew through voluntary efforts of people. She works full time without pay. She and others try to help the situations of single-parent poor families and homeless families. One effort is to help people find affordable housing.

Gene asked Lynn Ann if there might be something in her office that Pete could do. Lynn asked her other volunteers and together they came up with a job for Pete. Now several times a week, Pete's job is to go through apartment rental ads in local newspapers. When he finds

BEST COPY AVAILABLE

an ad below a certain dollar amount, Pete cuts it out. After going through all the ads, Pete organizes the ads by location and price and puts them into a 3-ring binder. When someone calls in need of housing, everyone uses Pete's book. As Lynn Ann says, "Pete is making a real difference in people's lives." She is planning to invite a family who finds a home through the book to come in and meet Pete. Lynn Ann feels that it is important for Pete to see his value to others.

When showing people Pete's book Lynn Ann, with pride, shows how he is getting better and better with organizing it. They saw at first that he was having trouble knowing where to paste the ads in. Their solution was to draw a grid on notebook paper and make lots of copies. Having the lines on the paper has helped Pete to do his job better.

Life in Lynn Ann's office has changed significantly since Pete arrived. There is a new spirit in the office. Lynn Ann says the best thing about having Pete there is simply him being himself. Pete's gift of gab is revered here, especially the jokes. Lynn Ann and Pete have a deal — Pete has to keep telling her jokes because she often gets too serious. In return Lynn Ann's promise is to be a good boss. When Pete yells over "Hey Lynn, I have a joke," the entire office comes to a hush. The punchline is delivered, everyone either laughs or moans — and then they get back to work.

Bonnie

Bonnie is a young black woman who is somewhat shy and timid. When she smiles it seems to cover her whole face. Bonnie spent about 24 of her 28 years in a state school and hospital. Bonnie needs a lot of assistance for most physical tasks except driving her electric wheelchair. I asked Sophie if she would spend time getting to know Bonnie and to think of how she could get involved in their community. Sophie invited Bonnie to be a member of a committee that was organizing a community festival. Bonnie was delighted. The one thing she couldn't believe is that none of the other residents living at our residential apartment program were doing it too. I remember her saying, "You mean it's just me, mine alone, no other clients?" Bonnie's jobs for the day were to greet people at the tea, hand out art awards at the children's art contest, and review the parade on the reviewing stand.

Let me insert here that all along I have tried to stay physically away from these community groups and events so as not to impose or intrude on the community's natural way of doing things. I decided in this case I would go to the celebration and imagined all these scenarios of Bonnie's Triumphant Day. The morning of the celebrations I

BEST COPY AVAILABLE

grabbed my daughter and off we went to blend into the crowd.

Well, my expectations differed a lot from what happened for Bonnie that day. She was physically present in all these activities but didn't really seem involved. She was introduced over the microphone at the art awards. People in the auditorium clapped but then she was just sort of ignored as things went on around her. I remember looking down at the ground and feeling embarrassed for her. Sophie wasn't there. I scanned everywhere for her but she was busy preparing for something else. Soon it was over.

The next day, I asked Bonnie how she felt. She told me she felt funny, like everyone was staring at her, and that she felt left out. She told me she didn't want to do anything like that again. I know Sophie felt bad that others hadn't really included Bonnie that day. She told Bonnie that she was glad she came and hoped next year Bonnie would help on the committee again. Bonnie smiled her immense smile and said she really wanted to try it again.

Some of the people in charge that day told Sophie they were surprised at how the children responded to Bonnie. They weren't afraid of her and gave her a big hand. They thought the kids would be afraid. Perhaps they didn't realize that it was they themselves who were afraid. There are several things that I make of this. Again I say it is not for me to judge — it is not my expectations that are important here. It is clear that individuals with severe disabilities will need to be supported in different ways as they come to be involved in communities. Why did we expect this woman who had lived in an institution for twenty-four years to feel self-assured on a stage alone in front of strangers? Now instead of being horrified I can compare it to my own feelings at walking into my first PTA meeting and not knowing a soul.

Bonnie also had this real desire to sing. Although her voice was quiet, it was a beautiful voice. Where might Bonnie find a place to sing? By now Gene was totally involved in our efforts. He thought that perhaps a church choir might be a place. Bonnie was definitely interested. Gene knew a woman named Gloria who is the matriarch of a large Baptist church. At eighty years old, Gloria has had a rather rough life. One of twenty-five children born to her parents in Alabama, Gloria had struck out on her own at thirteen. After moving to our area, marrying and having six children, she became very ill. She entered a hospital and stayed for five years. In the meantime her family got split up into foster homes and her husband took sick and died. All Gloria could think about in these years was getting well and reuniting her family. She says everyone pretty much decided she would die soon. Her response was to pray. She says it's hard to express how it felt to walk out of the hospital, find her children and bring them

home. She decided at that time that she was blessed and from then on decided to make it her business to "do right by people."

Gene asked Gloria, "Might your church be a place for Bonnie?" Gloria's response was that at her church the doors were open. Gloria asked the church elders, the pastor, and the deacons who all in turn asked the congregation to welcome Bonnie. And this they did.

Bonnie originally went to church with her attendant. But after a while the ushers and some others told the attendant that she needn't stay anymore. Bonnie could rely on them to help with anything she needed.

After a little while, Bonnie ran into some financial problems and also stopped going to church because her attendants had become unreliable. Gene told Gloria what was going on and again Gloria went to the deacons and congregation and asked, "What can we do?"

One day the deacons went to Bonnie's apartment and presented her with three hundred dollars. They had asked the church members if they would consider giving a dollar or two to help Bonnie pay her rent. They also said they had volunteers lined up to come and get Bonnie ready for church if it were necessary.

I heard that the day of Bonnie's baptism into the church was quite an event to see. It was different from any other baptism ever performed there. Faced with the problem of taking her wheelchair into the baptismal pool, the deacons conferred and decided on another way. There was some concern about the response of the church elders since they would be breaking down deeply rooted tradition. However, on the day of her baptism, Bonnie, draped in cloaks and doused with water, was met with a resounding eruption of applause.

Other Communities

After many of these experiences one automatically begins to ask, "Is this community a 'typical community'?" Maybe it was just some kind of fluke. Maybe I had just gotten lucky and stumbled into it by sheer chance. Or maybe not. Maybe, just maybe, it was an example of what one might find in other communities. Just walking through this tiny community you wouldn't immediately notice the climate of hospitality. It was there, but needed to be found. The finding part, tapping into the network that brought life, this was the most important thing. I went to another community to see what I could find there. One of the first persons I found was Eddie.

Eddie

Eddie is an energetic and loving nine-year-old boy. He loves to run

BEST COPY AVAILABLE

and play as other children do. Eddie also has Down Syndrome. When I first met Eddie's mother, Melanie, she was at a particularly low point. She and her husband had been embattled with our local school district over Eddie's right to go to his neighborhood school, rather than being bused out of the school district to a segregated classroom.

Melanie and her husband Ed had dreams for Eddie. They wanted him to grow up to be a contributing member of society. They wanted him to go out in the world with the support of family and friends — to be accepted — to feel love. They had fought his entire life to realize their dreams. Melanie and Ed tried to surround Eddie with activities that involved other typical kids. However, these activities usually involved children who were peers of Eddie's younger brother. Melanie wondered if kids his own age would accept him. Could he ever be invited to a birthday party, not because of his younger brother, but in his own right? The past summer had started with plans for Eddie to go to a special day camp for children with disabilities. But Melanie wondered if Eddie could "make it" at a regular day camp.

Rob is an enthusiastic young minister at a local church whom I had met at a friend's house. We discussed promoting the involvement of people with disabilities in their communities. Rob told me it was easier said than done. At the church, he is involved with children's activities. One year he had tried to get several children from a nearby home for children to come to the day camp he directs, and to make whatever accommodations were necessary for them to participate fully and equally. Yet the staff at the Children's Home threw out one roadblock after another. The same thing had happened with a local rehabilitation hospital. He had extended an open invitation for any patient at the hospital to come to services at their beautifully accessible church. No one has ever come. As we were departing, Rob said if there were anything he could ever do, to let him know.

After knowing Eddie for a while, I called Rob and asked if there might be a place for him at Rob's day camp. They had one spot left. After Melanie registered Eddie she called me and said, "It's all so strange. It was too easy! No one's ever just said 'yes' to Eddie." Before camp started Melanie discussed Eddie's abilities and style with Rob. Melanie was concerned that Eddie would get too tired going the full eight hours. Maybe she should pick him up early, she thought. Rob's response was "No problem. If he gets tired he can lie down in the nurse's office for a while and then rejoin us. Don't worry."

As camp proceeded I was struck by how nervous Eddie's mom was. Would he be kicked out because he's not a good swimmer? What if he wandered off? It was as if she were expecting a call any day to say that Eddie wasn't good enough. The call never came.

BEST COPY AVAILABLE

Eddie's behavior was not perfect, as no child's is. He did wander off sometimes. He didn't always listen to his camp counselor. One day, while painting, his particular painting extended to the floor of the church building. Still no call came. On the final day of camp, parents were invited to attend an awards ceremony and final celebration. Eddie received several awards for art and nature study. He also received the "non-swimmers free-style award." It wasn't the awards that struck Eddie's mom, however; it was the feeling in being there that day. Other children hugged Eddie and said they would miss him. A parent of one of the other children in Eddie's group came up to Melanie and said that Eddie's presence was the best thing about camp this year and thanked her for sending him. I mean, imagine it — being thanked for Eddie's presence. This was a new experience! Another parent said that she too was thankful for Eddie. She said that he brought out the best in her own child. Everyone said their good-byes. They also added, "Please come to camp next summer."

After camp was over, Eddie and his family were at a community festival. During the course of the evening several children came up to Eddie to talk. They were children who had met him at camp.

My own participation in Eddie's camp experience was minimal. I knew Eddie and I knew Rob. It was only a matter of connecting them. Together Rob, the camp counselors, the children and Eddie came to their own solutions. They did it their way — as it should be done. For me it meant trusting them and resisting the impulse to interfere and give professional advice. They felt no need to call on me. My involvement took the form of supporting Eddie's mom and helping her get through her underlying fear that Eddie "wouldn't be good enough" and would be rejected.

In a postscript to Eddie's story, word has come to his family that Eddie will be finally going to his neighborhood school this fall. Although his family knows that not all children will welcome him, it is the experience at camp that renews their faith that their son will find people in his life who will accept him as he is.

Shelly

Shelly is described by those who know her as a "doll." She's very friendly and very talkative. She lives in a residential program in a large suburb. Shelly has cerebral palsy and mental retardation. She uses a wheelchair and pretty much has to rely on other people for her physical care. Shelly wanted to be involved in something but her staff described her also as being terrified — she always backed out of everything.

Knowing that Gene knew some people in Shelly's community, I

BEST COPY AVAILABLE

decided to use this "trust network" again to find people there who would say "yes" to Shelly. After Gene had spent some time with Shelly, he found that the thing that she wanted more than anything was to find a way to help other people who had someone they loved die. About six months previously, Shelly had lost her boyfriend to cancer. She felt she knew something about what it feels like and could offer help to someone else who had those feelings.

Gene knew of several groups that met in her community which had as their focus supporting each other after this kind of experience. One met in a hospital, and one met in a church. Gene asked the leaders of both groups, and each said that Shelly would be welcome. Gene decided to take her the first time. When he called to tell her staff person at the residence, the meeting happened to fall on the same night Shelly was to see her psychologist. The staff person said they'd have to see if her psychologist would change her night. A return phone call indicated that no, the psychologist would not change and furthermore she felt that it was entirely inappropriate for Shelly to go. After all, Shelly couldn't even help herself. How could she help anyone else? She herself was in a "grief denial stage" and "inappropriately displayed her grief." On the basis of the psychologist's advice, the staff said that Shelly couldn't go. When Gene went to explain it to Shelly she cried. She was also angry — angry that she hadn't had a choice. It was really important to her. Shelly's staff encouraged her to talk to her psychologist about how she felt. I didn't know if she'd be able to. But she did.

I don't hesitate to say the psychologist seemed rather furious. The report that she sent to the county expressed her opinion that we were all unethical and incompetent. We were "interfering in Shelly's behavior program." The program was that Shelly was not allowed to talk about her grief to anyone except her psychologist. The psychologist told Shelly she could choose, it was her choice. She could keep seeing her, or she could go to the group. Shelly chose the group. The psychologist sent a report saying that this would be the last time the psychologist would see Shelly since she would be getting "treatment in a new therapeutic facility." Gene says that on Shelly's first night with the group she carried herself with such poise and class that he was knocked over. The group promptly kicked Gene out of their meeting since he had not lost anyone. When the doors opened again, he found Shelly surrounded. People were talking with her, laughing with her, being with her. Others came over to Gene and reassured him all had been well. What a delight Shelly was! How insightful Shelly was! Things couldn't have gone better. Shelly beamed and said, "I helped!"

BEST COPY AVAILABLE

The Project and Its Effects

Even though there is no book available on how to create caring in communities, when I started out I often wished for one. There was no way of knowing how and when I should offer support to the citizens who made commitments to get involved. I started out with the idea that I, as a human service worker, should be as invisible as possible. I've come to believe that sometimes this is true and sometimes it's not. Again, there was no one answer. The challenge became to discover what our role might be, finding the ways to not impose or change the natural flow of communities but to still somehow guide them in finding and being open to the contributions their members with disabilities could make.

At times some of it seemed easy. Finding Sophie, Frank, Gene and the others, and bringing people who wanted to contribute to their attention, was tapping into a world they were trying to create anyway. Their understanding of the life experiences of isolated people with disabilities was a wonderful thing to watch unfold. Meeting regularly at the deli and hearing their many stories seemed to be an important supporting role for me to take. Also, taking the time to learn about their perceptions of their community generally was a part of the support which evolved. Several times I helped unload a pickup truck of food for the food pantry. I needed to have an understanding of their "work." Listening to their concerns and their solutions, not being this "expert" was all a part of it.

On the other hand, some experiences were pretty tough. One woman from a community group that had agreed to help began, instead of working in her neighborhoods, to visit people at our agency building. Next, she wanted to and did attend several professional "staffings" held about the people she was trying to connect. I was at a loss for what to do. It appeared to me that she was starting to get sucked into the human service world. I had told her that I was placing trust in her. Yet what should I do when I felt the focus of our efforts drifting? Was I trying to be the "expert" or was it a legitimate concern? In this particular situation, I made the decision to talk with her about my concerns. This discussion led to defensiveness, probably on both of our parts. She began to feel a lack of support from me.

As we worked through this, many things became clearer. First, she was feeling isolated even within her own community organization. Her efforts at getting involvement from others in her group had fallen on deaf ears. Also, she was becoming disillusioned with many people from her community who she thought would be open to accepting people with disabilities.

BEST COPY AVAILABLE

Rejection was slapping her in the face. The human service world became an attractive alternative since it was a place that was used to the presence of disabled people.

My chosen role of being in the background had been the wrong role in this instance. A stronger presence was called for and I hadn't seen it. The turning point came when she finally found an ally, someone to share in her efforts just as Sophie had Frank and Frank had Gene. Then she stopped trying to be with human service workers and started being with people from community organizations.

Fertile Ground

There is something to be said here about fertile ground. Just as new seeds cannot sprout and grow and bloom without nourishing soil, a project such as Citizen Participation cannot flourish without a supportive backdrop.

In my agency a climate of experimentation was encouraged. The soil had been nourished and tilled so that new ideas could grow. There were space and encouragement from leadership to be creative, bold, and even audacious. There is no doubt in my mind that without these ingredients, the seed of citizen participation might never have sprouted and, if by chance it did, it would have died from lack of nourishment.

Even with the fertile soil, the project itself appeared to be just this very tiny effort in the complex workings of a very large agency. But it is also possible that this insignificantly small project also represented a seed of change.

My own feeling about change was that it was natural, important and necessary. I guess what I realize now that I didn't realize then, was that there seems to be a direct relationship between change and conflict.

Something started to happen at my agency that I find very hard to describe. First, it's hard to say positively that this citizen participation project was the only variable operating that was responsible for change. But it was important, somehow. Second, there are all kinds of emotions that get wrapped up in change — feelings of joy and excitement as well as anger and pain. Finally, I'm sure others who were there would have their own valid perspectives on what was changing, what it meant, and whether it was good or bad. I respect those perspectives. But all I can do here is share how it looked, seemed and felt through my own eyes.

I can say with all certainty that the citizen participation project, which is really about Sophie, Frank, Albert, Pete, Eddie, Rob and the others, changed my life. The change was not reflected only when I was

BEST COPY AVAILABLE

at work or only in my personal life. Somehow the change blurred these two aspects.

The stories that unfolded as people with disabilities and other citizens from their communities came together challenged the very foundation of my human service world. Those who were once clients were now evolving into citizens. Those who were untrained, inexperienced and, up to now, seen as unwilling, were now leading the way for those (including myself) who had viewed themselves as highly professional, experienced, specialized experts. Everyday simple solutions and wisdom replaced professionally driven answers. Those who always felt they knew the most knew the least. Specialized training was replaced by human caring.

In the citizen participation project, jargon was replaced by everyday language. Lists of needs and deficits got pushed aside for talents, hidden gifts and desires. Assessments in the service world got replaced by getting to know a person in the citizen world. I could go on and on but I think the message is there. Somehow our experiences started eroding the fundamental beliefs that are probably a part of every single human service agency alive. It was like knocking out the pillars of the structure one by one.

Given that citizen participation was something none of us had expertise in, and given that I was a person responsible for learning how it might work, I can tell you it was very lonely work. As my own fundamental ideas were eroding and being replaced, I found myself feeling like an alien in my own agency. I felt that no one understood what I was talking about anymore, yet I wanted so much to share it. There seemed so much resistance to these new ideas. I struggled to find words. I felt walls building between myself and many of my colleagues. I didn't want the walls there at all, yet I knew that in reality I was laying some of the mortar. The more we talked about "a new way of thinking" the higher the walls seemed. On both sides of the wall there was uncertainty, anger and self-doubt.

I struggled with many questions. How much of the conflict was me — my personality, my style? How much of it was the sheer confusion of a new undertaking? Part of the confusion may have been my colleagues'. How could I be saying this, that and the other thing just last year and now, all of a sudden, be saying something so entirely different? I also wondered how much of it was just what we were discovering and sharing. Would it have mattered who was saying and thinking all these new things? Was it just the fact that they were being said?

I remember calling our sponsors at the Developmental Disabilities Planning Council to ask them if I was losing my mind. Behind closed

BEST COPY AVAILABLE

doors I would ask my boss if there were something wrong with me. The feelings I had were that of being an outcast. I shut the door to my office and cried a lot.

Here we all were with our foundations cracking and walls built, trying to somehow relate to each other and trying to figure out what all of this had to do with our mission. Along the way, we asked for help from the Commonwealth Institute, funded by the Council to help people like us explore our values. They came and did some workshops. The conflict continued and even escalated, bringing us to the very edge of dysfunctionality. Anger increased; factions formed. The leadership struggled to help everyone work it through. Maybe this had to happen. Maybe we had to get to a place of real conflict before we could begin to build something new.

Other things, good things, were happening too. For me, when blocks in the wall broke, it allowed me to find other people in my agency who were also starting to question their foundations. They were also struggling. Then the Council and the Commonwealth Institute connected me with others in the state and in the country who were also asking themselves if they weren't a little out of their minds to be thinking the things they were. We started to meet. This network became a lifeline for me. I was fortunate too, because my boss always listened and told me that I had something important to offer, no matter how much trouble I was helping to stir up for him. I was fortunate to have the support of my husband, children and friends. I felt myself becoming a better citizen in my own community. I saw people with disabilities and their friends working together and caring for each other in a way that I had never thought possible. It made all of it worth it.

In the tiny town with a funny name life goes on. Frank's and Sophie's formal "project" with us is done but they are still there, open and willing to lead me to others — to do what they can — to do what seems natural to them. They keep doing what they always have done, but now with people with disabilities too. They told me that their community is enriched by the contributions of Albert, Pete and the others. One day Sophie told me that she finally understood why the people with disabilities she invited to that tea long ago didn't come. She says that knowing Bonnie has helped her see that people who have been very isolated are afraid they won't be welcomed. Frank and Sophie say that we need to find more ways for people to feel welcome. They think that every community needs to think about this.

Through Frank and the others we are learning something significant about the art of asking. Frank tells this story about being appointed as chairperson of his church's historical committee. He had

BEST COPY AVAILABLE

noticed that the group was composed of the same people who are on every other committee. It seemed that these same people were the only ones involved in anything. Frank decided to — as he describes it — "go a-calling." He called on people who never got involved in anything. He called, in particular, on the church's oldest members. It made sense to him that they had a unique perspective to offer. Their gift wasn't their ability to research the history. Their gift was that they had lived the history. He told them how the church needed their knowledge. Twelve new committee members were found, all of them over age seventy. They were delighted that someone had asked them to be a part of it. Frank says that often people don't realize they have something to offer.

So what is the "theory" of this art of asking anyway? To get people involved, Frank says, you first have to let them know that they have something valuable to offer. Then you ask them. Period.

These days when I go to the deli, I often meet with Gene. He is formally working with me to help neighboring communities find ways to welcome people with disabilities. There are some new possibilities emerging. A very exciting development is the formation of a group of people from neighboring communities who have gotten interested in starting a citizen advocacy office to be a focus for their "connecting" work. The group includes many of the people I have talked about here, other community leaders, and a local priest. They are visiting citizen advocacy offices in other Pennsylvania communities and are considering applying to the Council for a grant to get it started.

The majority of people we have helped to connect with groups in the community are still involved in them. I still hear great stories of people making contributions, about personal relationships, and about growth.

At my agency we're still struggling. A recent retreat helped us all think about the guiding principles and values that we hold as most important. We need to be careful. We need to be thoughtful. And we need to be open. We need to be careful we don't come to the conclusion that the only thing that the people that we serve need is a few community friends and connections, and everything will be fixed. We need to be open in order to learn from each other and to listen to the dreams and desires of those we serve. Ultimately, I don't know what will happen. But I don't think we will ever be the same.

As for me, I am constantly learning and constantly struggling. Maybe it will just always be this way. I want to say something like "I can never go back." It's like when you've been looking at the little symbol on your credit card and then you squint and you look at it from

BEST COPY AVAILABLE

another angle. You find that there is this different symbol. It is a hologram. You hadn't seen it in all the times you've looked at that card, and now all of a sudden it will never look like the same thing again.

For all the times I wished I had a manual on how to do my job, I hope now that one is never published. I feel as if I need to protect something — an endangered species, if you will. To professionalize, objectify, assess and impose human service structures on communities is wrong. It's already happened too much. That's why people find it so unusual to hear about the Sophies, Franks and Glorias that I have been so fortunate to meet and learn from. I find hope in their ways, their wisdom and their stories. It is not just a hope for the lives of people with disabilities. People caring for people; people being welcomed and revered for their uniqueness and contributions; people building better communities — that is the promise for all of us. And all you have to do, to get it started, is to ask.

BEST COPY AVAILABLE

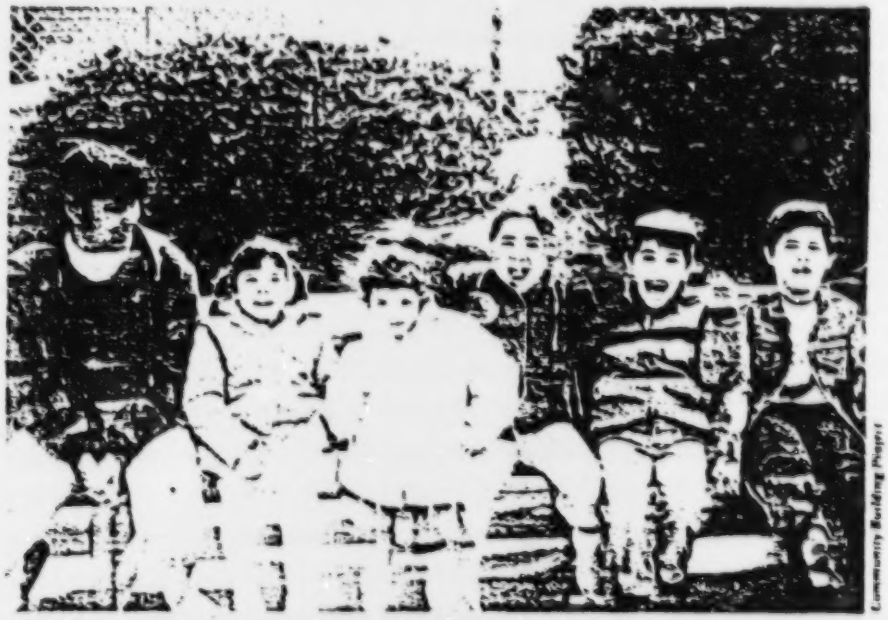
"Community Building" in a Chicago Neighborhood

by

Michael Ervin

'Community Building' in a Chicago Neighborhood

A small project in Chicago's Logan Square works to involve people with disabilities in the ordinary life of the community. In the process, it has started people thinking just what "community" is all about.



Miss Marguerita helps out with the children at Lutheran Day Nursery.

by Michael Ervin

A Chicago neighborhood organization has been trying out an unusual "community building" strategy over the past year, and so far the results, as displayed at this summer's annual congress, have surprised everyone—including the organization's leaders themselves.

Logan Square Neighborhood Association, on Chicago's Near Northwest Side, agreed to be the host for a neighborhood-based effort to bring people with disabilities into the ordinary, everyday life of the community. The project involves linking residents of local group homes with other neighborhood people who agree to serve as "guides to the community." Another aspect is connecting people with disabilities with such local institutions as churches, schools, bowling leagues, or park programs. "It's really about building neighborliness," explains project director Kathy Bartholomew-Lorimer. "We're nurturing a piece of community life that often gets ignored."

Mike Ervin is a Chicago area freelance writer.

BEST COPY AVAILABLE

Guides and Connections

The guides include people like Clara Lyle, a local block club leader, who has established a friendship with Karen, who lives with her elderly parents in Logan Square but had little contact with her neighbors. Clara and Karen share simple pleasures, like bowling or shopping or planting flowers. Clara has introduced Karen to her neighbors and members of her block club, and got her signed up as a deputy voter registrar. Long-time Logan Square residents Mary Lou Riaz and her husband Jerry became friends with June, who lived until recently in a local group home. They introduced June into their church, Avondale Presbyterian.

Similar connections have been established for people like Frank, an elderly man who lives in a group home. Frank likes to bowl but had no chance to do so, so the project hooked him up with a bowling league organized out of St. Sylvester's Church. Other project participants volunteer their services at local institutions. One man helps out in the mail room at Norwegian-American Hospital, others volunteer at a local boys and girls club, pet shop, and daycare center.

Such connections may seem simple, but they are in their own way extraordinary. Typically, explains Bartholomew-Lorimer, people with disabilities like mental retardation are part of their communities in physical presence only; socially, they are completely segregated. The assumption is that they are "special" people needing "special" homes, education, recreation, religious programs. But the "special" treatment effectively cuts them off from "nonspecial" people around them—friends and neighbors—and at the same time deprives the community of the talents and energies of the disabled people themselves.

Aftermath of Deinstitutionalization

In some city neighborhoods, like Chicago's Logan Square, Uptown, and Rogers Park, there is an added twist: some property owners and other residents have in the past fought the establishment of group homes, along with halfway houses and other similar institutions, as a threat to the residential character of the neighborhood. Earlier waves of "deinstitutionalization" left bad memories, so that people with disabilities were viewed as "outsiders" with no real place in the neighborhood.

But every neighborhood has families with members that have some kind of disability: it's the institutionalization process itself that defines them as outsiders, says Bartholomew-Lorimer. Just how effective that isolation is became clear when Bartholomew-Lorimer began talking with people in and around Logan Square a year ago, as she was getting the project started. "I talked to over 100 people," she says, "and there were probably two or three who knew a person with a disability."

Those conversations ranged beyond the specifics of disability into broader questions of community. Several residents expressed an underlying anxiety over the loss of a sense of community, of neighborliness. It was for that reason, among many others, that the decision was made to ask LSNA—rather than a social service agency, for example—to sponsor the project. "The work of bringing people into opportunities where they can be seen as a neighbor or friend is community work," says Bartholomew-Lorimer. She also wanted to avoid having her efforts characterized as a "service" project, to attack the isolating stigma that the proper place for people with disabilities is under the wings of service providers.

Board Skepticism

But the LSNA board did not automatically embrace the project. They were sure it was a worthy effort, says former board chairman Luis Moya, they just weren't sure it fit within their mission. LSNA draws on traditional organizing tactics of confronting a specific problem or enemy, working on such issues as housing and crime. They saw the community building project as direct service, Moya says. "That's not what we're in business for. We help people look for their own solutions rather than present them with solutions."

But Bartholomew-Lorimer persuaded the board and then-executive director Joe Mariano (who has since left) that the community building project was an exercise in empowerment, freeing people from institutional subservience and making them active participants in a community from which they were previously shut out. Moya became convinced when he saw the link.

Results of the project's first year were displayed in a slide show and active participation by project participants at the LSNA annual congress in May of this year, and met with an enthusiastic reception. Mary Ellen Croteau, a local artist and neighborhood activist, spoke movingly of her involvement in the project. Said Croteau, "I believe the question of what to do with vulnerable people is the ultimate challenge in our communities, and the solution will make our neigh-

Community Building Project

Earl (center) helps out in the game room at Logan Square Boys and Girls Club, where he puts his exceptional facility with numbers and letters to good use.

BEST COPY AVAILABLE

Community Building Project

Eddie (above) runs a regular mail-delivery service at Norwegian-American Hospital. Frank (third from left) has become a regular Sunday-night bowler with a local bowling league. Team members help arrange rides when he needs one, and invited him to the League Banquet in June.

borhoods strong. Because we need each other. And we get strength from caring for each other."

Capacity Buidling

Altogether, 26 people with disabilities are participating in the project. Their levels of participation vary as greatly as their personalities and talents do. The project is designed to be "capacity-oriented," focusing on people's abilities and interests. This is in contrast to the human service system which, according to Bartholomew-Lorimer, "groups people according to common deficits—it's easier to manage that way."

The "capacity-oriented" model is based in part on the work of Northwestern University Professor John McKnight. (The university provides the staff and serves as fiscal agent for the project, which is funded by the State of Illinois.) McKnight argues that not only people with disabilities, but also low-income city neighborhoods themselves are viewed according to their problems, rather than their capacities. Such a focus, argues McKnight, leads to the creation of programs and services to "solve" the problems—rather than the organizing and empowerment of people to create their own solutions and opportunities.

Other efforts to bring people with disabilities into community life are underway in different parts of the United States and Canada. The Chicago project is unique in that it is sponsored by a community organization, rather than an organization focused on issues of disability.

Mova says the benefit for LSNA from its involvement in the community-building project is in part that the project gives community residents a broader, more positive picture of what LSNA is all about. And he adds that the community benefits from unique contributions of people like Karen or Frank or June. That reciprocal element is key to the community building project. As Bartholomew-Lorimer notes, citizenship, real involvement in a community, is a two-way street.

FOR MORE INFO

Kathy Bartholomew-Lorimer, Community Building Project, Logan Square Neighborhood Association, 3321 West Wrightwood, Chicago IL 60647, (312) 384-4370.

Finding Community Connections

Getting Connected: How to Find Out About Groups and Organizations in Your Neighborhood is a manual on investigating neighborhood connections. It reports on the efforts of the Community Life Project to identify community connections in Chicago's Logan Square Neighborhood. While the appendix information is Chicago-oriented, the general strategy and support documents will be easy to use in any city. 32 pages. $2.50.

FOR MORE INFO

Center for Urban Affairs and Policy Research, Northwestern Univ., 2040 Sheridan Road, Evanston, Ill. 60201.

BEST COPY AVAILABLE

ANNOTATED BIBLIOGRAPHY

TITLE: Enhancing the social inclusion of persons with developmental disabilities

AUTHORS: Abery, B. H., & Fahnestock, M.

PUBLICATION INFORMATION: 1994

In M. F. Hayden & B. H. Abery (Eds.), Challenges for a service system in transition (pp. 83-119). Baltimore: Paul H. Brookes Publishing Co.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
http://www.pbrookes.com

The authors stress the importance of a wide variety of types of social relationships in people's lives. The chapter begins with a discussion of the nature of social relationships. It elaborates on issues related to social relationships and networks, including a review of related research. A person-centered approach to the development of social relationships is advocated, with examples and strategies offered.

TITLE: Friendships and community connections between people with and without developmental disabilities

AUTHOR: Amado, A.N. (Ed.)

PUBLICATION INFORMATION: 1993

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
http://www.pbrookes.com

This book contains chapters that discuss a wide variety of critical issues related to friendship and people with developmental disabilities. It is acknowledged that

"supporting friendships can be fragile, delicate, magical, and sensitive work. It is not work that easily fits into formalized systems and agency patterns" (p. 373). Authors discuss dilemmas and challenges related to this.

The book is divided into three sections: (1) dimensions of friendships, (2) stories of friendships and (3) strategies for building friendships. Chapters in the first section include an introductory piece by John O'Brien and Connie Lyle O'Brien discussing dimension of friendship, issues of attraction and power, and context of community; loneliness; intimacy and sexual relationships; the gendered context of friendships; and friendships between "staff" and "clients." The second section contains stories of friendship written by people with disabilities, parents, and advocates from within and outside of the service system. Finally, chapters in the third section offer important strategies based upon focused efforts to assist people to form friendships and connections at work, in community associations, and within the community at large.

TITLE: Amistad: Stories of Hispanic children with disabilities and their friendships

AUTHOR: Beach Center on Families and Disability

PUBLICATION INFORMATION: 1997

Beach Center on Families and Disability
University of Kansas
3111 Haworth
Lawrence, KS 66045
voice/tdd 913-864-7600 fax 913-864-7605
beach@dole.lsi.ukans.edu
http://www.lsi.ukans.edu/beach/beachhp.htm

This monograph, aimed primarily for families and educators, is the result of a study on friendship that focused on the Hispanic population. The intent was to find examples of "successful" friendships for children who experience significant disability. The stories are presented here, followed by a concluding section outlining "friendship tips" and giving additional resources.

TITLE: When spider webs unite: Challenging articles and essays on community, diversity and inclusion

AUTHOR: Asante, S.

PUBLICATION INFORMATION: 1997

Inclusion Press
24 Thome Crescent
Toronto, ON M6H 2S5
CANADA
416-658-5363 fax 416-658-5067
includer@idirect.com
http://www.inclusion.com/

Shafik Asante was a leader in organizing to fight against injustices in the African American community, as well as in the struggle for better community services. He lectured internationally to diverse groups on community organizing and alliance building. Topics addressed in this book include alliance building, inclusive community building, disability issues, and leadership and organizing, among others. The essays are based on reflections on the author's personal and work experiences.

TITLE: Building stronger communities for all: Thoughts about community participation for people with developmental disabilities

AUTHORS: Bogdan, R., & Taylor, S.J.

PUBLICATION INFORMATION: 2001

In A. Tymchuk, K. Charlie Lakin, & R. Luckasson (Eds.), The forgotten generation: The status and challenges of adults with mild cognitive limitations (pp. 191-199). Baltimore: Paul H. Brookes Publishing Co.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
http://www.pbrookes.com

The authors question how can we think about having people with disabilities be a part of the community when community has become such a problem for everyone else, when community is under siege? They suggest that we must approach the challenge of helping people with disabilities to become part of the community with full appreciation of what is at stake. Thinking about community for people with developmental disabilities might help us think about it for ourselves. This essay presents some thoughts and observations on what it means for people with developmental disabilities to be part of the community.

TITLE: Toward a sociology of acceptance: The other side of the study of deviance

AUTHORS: Bogdan, R., & Taylor, S.

PUBLICATION INFORMATION: 1987, Fall

Social Policy, 18(2), 34-39.

For a quarter century sociologists have concentrated on stigma and the labeling and rejection of people with negatively valued physical, mental, and behavioral differences. Yet, the authors argue that individuals with a wide range of differences regularly form close relationships with typical people. No attribute of a person, no matter how atypical, precludes accepting relations. Thus, the sociology of acceptance is directed toward understanding not only how people with deviant attributes come to be accepted in personal relationships, but also in groups, organizations, communities, and society.

TITLE: On the road to community inclusion
and
On the road (again) to community inclusion: It's about time

AUTHORS: The Elizabeth M. Boggs Center on Developmental Disabilities

PUBLICATION INFORMATION: 1999 & 2000

The Elizabeth M. Boggs Center on Developmental Disabilities
University of Medicine and Dentistry of New Jersey
Robert Wood Johnson Medical School
335 George St., P.O. Box 2688
New Brunswick, NJ 08903-2688
732-235-9300 TDD 732-235-9328 fax 732-235-9330
boggsweb@umdnj.edu
http://rwjms.umdnj.edu/boggscenter/

These two booklets were produced based on community-building forums and conferences sponsored by The Boggs Center-UAP. They are the compilation of many short reflections on community and community building by participants in these events, including direct support staff, people with disabilities, family members, and others who have an interest in issues related to community building.

TITLE: The social basis of community care

AUTHOR: Bulmer, M.

PUBLICATION INFORMATION: 1987--out of print

Allen & Unwin, Inc.
8 Winchester Place
Winchester, MA 01890

This book analyzes the relationship between ideas about community life and the impact of social policy, demonstrating that, at least in England, there is "a vacuum at the heart of care policy which is likely to lead to ineffective or deteriorating provision of services" (p. ix). Bulmer's analysis is very relevant to North American discussions about community integration of people with disabilities. The book focuses more on informal support or care than on services and service systems, but he looks at both and at the interface between the two types of care in the community. His analysis draws heavily on a variety of research studies conducted in neighborhoods, within groups of families, and in other aspects of community life and is a major contribution to the discussion about community integration.

TITLE: Involving all neighbors: Building inclusive communities in Seattle

AUTHOR: Carlson, C.

PUBLICATION INFORMATION: 1990

Seattle Department of Neighborhoods
700 3rd Avenue
Arctic Building, Suite 400
Seattle, WA 98104-1848
206-684-0464
http://www.ci.seattle.wa.us/don/home.htm

This booklet was produced through the collaboration of the Seattle Department of Neighborhoods and the Washington State Division of Developmental Disabilities. It documents the "Involving All Neighbors" program, a program to promote neighborhood involvement by people with disabilities. One unique aspect of this program is that it is located not within a disability agency, but within the City of Seattle's Department of Neighborhoods.

The booklet contains many different examples of people's involvement in neighborhoods, including individual connections as well as participation in neighborhood organizations and projects. The stories are accompanied by reflections on some of the lessons learned.

A conclusion offers some overall lessons learned from the "Involving All Neighbors" program, and the appendix contains the mission of the Department of Neighborhoods, and a summary of key aspects related to what makes neighborhood organizations inclusive, qualities of community connectors, and suggestions for ways that neighborhood organizations can include people with developmental disabilities.

Overall, this booklet contains many diverse examples of neighborhood involvement and reflections and lessons based on these experiences. As such, it offers creative ideas and strategies for all those who are interested in helping to promote community connections and meaningful community participation for people with developmental disabilities. Finally, it provides a wonderful example of partnership between community and disability focused organizations.

TITLE: Interdependence: The route to community (2nd ed.)

AUTHOR: Condeluci, A.

PUBLICATION INFORMATION: 1995

CRC Press LLC
2000 NW Corporate Boulevard
Boca Raton, FL 33431-9868
1-800-272-7737 fax 1-800-374-3401
orders@crcpress.com
http://www.crcpress.com/us/

The book begins with a discussion of disempowerment--the ways people lose power and are oppressed and stereotyped. This discussion concludes with some lessons about change from the civil rights movement. Chapter 2 describes various paradigms within human services, including the medical, educational, economic, and maintenance paradigms. The next chapter outlines an alternative paradigm--the interdependence paradigm. In summary, the three goals of this paradigm are acceptance, relationships, and opportunity. Chapter 4 details four factors that are key to achieving interdependence: role competency enhancement, supplemental supports, relationship building, and systems advocacy. The fifth chapter focuses on "understanding community." It describes various functions of community, formal and informal dimensions of community, community space issues, communication issues, and learning about community issues.

TITLE: It's about relationships

AUTHOR: Forest, M.

PUBLICATION INFORMATION: 1990

In L. Meyer, C. Peck & L. Brown (Eds.), Critical issues in the lives of people with disabilities (pp. 399-408). Baltimore: Paul H. Brookes Publishing Co.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
http://www.pbrookes.com

This is a personal reflection by Marsha Forest on the many relationships that have enriched her life and the lives of her friends and family members. Interwoven with the personal stories are stories about integrating students with disabilities into regular schools. Forest points out how much we all have to give each other, and how much we miss when people with perceived differences are excluded from schools, neighborhoods, and friendship circles.

TITLE: The common thread: A collection of writings about friendships, relationships, and community life

AUTHORS: Gretz, S., & Ploof, D. (Eds.).

PUBLICATION INFORMATION: 1999

Pennsylvania Developmental Disabilities Council
Room 559, Forum Building
Commonwealth Avenue
Harrisburg, PA 17120
717-787-6057
info@paddc.org
http://www.paddc.org/

The stories in the monograph were originally published in a newsletter, "The Common Thread." The newsletter grew out of the work of the editors and others as

part of the Community and Relationship Building Project at the UCP of Pittsburgh, a project funded through a grant from the Pennsylvania Developmental Disabilities Council. The purpose of the newsletter was to share stories about community connections and relationships and in doing so to stimulate readers to think more deeply about these aspects of human social life. In reflecting on the significance of the title of the newsletter and this monograph, the editors' write: "There are many things operating in today's society which work against a strong social fabric. Many of us feel deeply that when some people are excluded from the life of a community, the social fabric contains a hole. Perhaps each of our efforts can be considered to be weaving threads that have the potential to repair the hold and make some of our communities WHOLE--at least in some places and for some people."

TITLE: Everyone here spoke sign language: Hereditary deafness on Martha's Vineyard

AUTHOR: Groce, N. E.

PUBLICATION INFORMATION: 1985

Harvard University Press
79 Garden Street
Cambridge, MA 02138
617-495-2577 fax 617-495-5898
http://www.hup.harvard.edu/

This ethno-historical study is an excellent portrayal of community life for deaf and hearing individuals of Martha's Vineyard. The reader is presented with the history of how the deafness was brought to the island. The book allows the reader to view the typicality of the lives of Islanders who were deaf, typicality due to the community's acceptance and ability to communicate with them. Groce takes us beyond the confines of medical or social definitions of deviancy and offers evidence that our pre-conceived stereotypes of what a disability may mean are really determined by the social construct we create as a society.

This well-researched book is a must, not only for people interested in the field of disabilities but for anyone trying to struggle with integration into community life. The book is a simple thesis offering a profound message in a wide array of disciplines. It will add thought to issues that will remain unresolved and discussed for a long time to come.

TITLE: A guide to building community membership for older adults with disabilities

AUTHORS: Harlan, J., Todd, J., & Holtz, P.

PUBLICATION INFORMATION: 2001

Training Resource Network, Inc.
P.O. Box 439
St. Augustine, FL 32085-0439
1-866-823-9800 fax: 904-823-3554
info@trninc.com
http://www.trninc.com/

This publication is intended as a resource of ideas, tools, and techniques that have been found to be effective in helping to promote community membership for older adults with disabilities. Examples and stories are drawn from experiences of community builders and individuals with mental retardation and other disabilities who participated in a demonstration component of The Community Membership Project, a training initiative grant funded by the Administration on Developmental Disabilities and awarded to the Center for Aging Persons with Developmental Disabilities at the University Affiliated Program of Indiana. The stories are interwoven with information and interactive training activities, based on a community-building approach. The information in the guide is applicable to supporting people of all ages in community membership.

TITLE: Friends: A manual for connecting persons with disabilities and community members

AUTHOR: Human Services Research and Development Center

PUBLICATION INFORMATION:

Human Services Research and Development Center
Minnesota Developmental Disabilities Council
300 Centennial Office Building, 658 Cedar Street
St. Paul, MN 55155

This manual grew out of the "Friends" project, a one-year grant project sponsored in 1989-90 by the Human Services Research and Development Center of St. Paul, Minnesota, and funded by the Minnesota Governor's Planning Council on

Developmental Disabilities. The purpose of the project was to learn about and develop methods for the staff of residential service agencies to support people with disabilities in establishing friendships and relationships with nondisabled people in their communities and to assist people with disabilities in being more a part of their communities.

Sections of the manual contain information on: planning with people; strategies to facilitate connections; introducing people; providing continuing support for relationships and friendships; assisting others in meeting and becoming friends with persons with disabilities; and agency support for relationship building. It describes the process used in the Friends project, strategies that seemed to be more and less effective, and it contains many stories and examples.

The manual would be useful for anyone who is interested in supporting a person with disabilities to widen his or her circle of relationships and to develop deeper friendships.

TITLE: Building communities from the inside out: A path toward finding and mobilizing a community's assets

AUTHORS: Kretzmann, J. P., & McKnight, J. L.

PUBLICATION INFORMATION: 1993

Institute for Policy Research
Northwestern University
2040 Sheridan Road
Evanston, IL 60208
847-491-8712 fax: 847-491-9916
http://www.northwestern.edu/IPR/index.html

This guide provides many stories, strategies, and resources related to building stronger communities. This involves looking at the capacities and contributions of all community members, including youth, people with disabilities, and older people, among others.

Chapter 1, "Releasing Individual Capacities," introduces ways to find and use the gifts and talents of local people. Chapter 2, "Releasing the Power of Local Associations and Organizations," describes the efforts of community associations to solve local problems. Chapter 3, "Capturing Local Institutions for Community Building," provides examples of ways in which local institutions (e.g., parks, libraries, schools, colleges) form community partnerships with each other. Chapter 4, "Rebuilding the Community Economy," highlights ways in which communities can capture and build upon existing economic assets. Chapter 5, "Asset-Based Community Development: Mobilizing an Entire Community," summarizes the community-building process presented in this

book. Finally, Chapter 6, "Providing Support for Asset-Based Development: Policies and Guidelines," suggests ways in which people and institutions from outside the community can support asset-based community-building activity.

TITLE: Affectionate bonds: What we can learn by listening to friends

AUTHOR: Lutfiyya, Z. M.

PUBLICATION INFORMATION: 1990

Syracuse, NY: Center on Human Policy, Syracuse University.

In this monograph, Zana Lutfiyya describes a qualitative study conducted with four pairs of friends in the Syracuse area. In each of these pairs, one person has a disability label and one does not. The author offers perspectives on friendship found in the literature, describes each of her informants and their friendships, explores the dimensions and characteristics of friendship, and relates the rights, responsibilities and obligations of friendship in her informants' eyes. She discusses how some friendships move toward greater intimacy while others stay the same or die away, and lays out some of the implications of her study for the human service world, for families, and for people thinking about their own friendships. This ground-breaking study should begin to focus our thinking on what really goes on in friendships, including those between people with and without disabilities.

TITLE: "A feeling of being connected": Friendships between people with and without learning difficulties

AUTHOR: Lutfiyya, Z.M.

PUBLICATION INFORMATION: 1991

Disability, Handicap & Society, 6(3), 233-245

Recently, programmatic attempts to encourage close ties between people with learning difficulties and typical citizens have increased. It is believed that such relationships will extend the assimilation of people with learning difficulties into society. The researcher presents the perspectives of four pairs of friends about the meaning of their friendships. The informants shared similar ideas and expectations about the characteristics of friendship in general. These included its mutual, exclusive, and voluntary nature; the rights, obligations, and responsibilities of friends to each other; and the positive regard or affection found between friends. Despite efforts on the

part of service providers to support the development of friendship between people with and without learning difficulties, the biggest barriers for the individuals in this study were the practices of the human service system, which curtailed opportunities for people which would have promoted the development and maintenance of friendships.

TITLE: Making friends: The influences of culture and development

EDITORS: Meyer, L. H., Park, H. S., Grenot-Scheyer, M., Schwartz, I. S., & Harry, B.

PUBLICATION INFORMATION: 1998

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
http://www.pbrookes.com

Based on qualitative research, this volume offers a wealth of information, strategies, and perspectives related to promoting friendships for students with severe disabilities. Perspectives range from those of people with disabilities, family members, teachers, and researchers. Chapters address issues related to friendship and cultural diversity, challenging behaviors, students who are deaf-blind, classroom structure and interactive opportunities, and many others. Issues related to promoting friendships are discussed across the range of school years, from preschool through high school. As friendships are a vital component of schools, and of the concept of inclusion, this is a valuable resource for all those who are concerned with creating schools that promote true inclusion.

TITLE: What are we learning about bridge-building?

AUTHORS: Mount, B., Beeman, P., & Ducharme, G.

PUBLICATION INFORMATION: 1988

Communitas, Inc.
730 Main Street
Manchester, CT 06040

This monograph opens with the key premise of "bridge-building." "Real integration, the development of genuine networks of support, requires very focused

and assertive effort(s) on behalf of facilitators who initiate, support and maintain new relationships. We call these facilitators "bridge-builders" because they build bridges and guide people into new relationships, new places, and new opportunities in life" (p. 1).

As the sub-title of the monograph suggests, it is a summary of a dialogue between people who are trying to build community for people with disabilities by working as bridge-builders. Most of the monograph presents the reflections of five participants at a day-long discussion on bridge-building in 1988. As this publication appears to be a faithful rendering of people's words, with little attempt at a full written explication of the concepts and terms that form the new language of bridge-building, it may be unsatisfying for someone who is completely new to the idea. However, it does contrast the different perspectives held by proponents of traditional human services with that of bridge-building, and would be of interest to those readers already acquainted with this concept.

TITLE: What are we learning about circles of support?

AUTHORS: Mount, B., Beeman, P., & Ducharme, G.

PUBLICATION INFORMATION: 1988

Communitas, Inc.
730 Main Street
Manchester, CT 06040

The authors offer the experiences of several "circles of support" now in existence in Connecticut. Inspired by the efforts of the Joshua Committee over the past decade, the authors helped found circles of support around several people with disabilities. "A circle of support is a group of people who agree to meet on a regular basis to help the person with a disability accomplish certain personal visions or goals" (p. 3). The monograph gives practical information on the process of starting and maintaining a support circle, with several actual examples. Circles of support serves well as both an introduction to the concept and as a useful resource for people already familiar with the issue.

Acknowledging the current fascination with "personal futures planning," the authors provide an important comparison of support circles with person-centered and traditional methods of service planning. And they wisely caution that the process outlined in the monograph is not meant as a model for replication of other support circles. Rather, "the spirit of a circle...is more important than the details of the process, and we hope that the process we describe will help people invite the spirit of support into the lives of other people" (p. 1).

TITLE: Nasty girls, thugs, and humans like us: Social relations between severely disabled and nondisabled students in high school

AUTHOR: Murray-Seegert, C.

PUBLICATION INFORMATION: 1989

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
http://www.pbrookes.com

Based on a qualitative research study, this book is the account of one school's move toward integration, and the peer relations that developed in that school as a result. The author documents the ways in which the school's integration efforts affected student relations and teacher practices. In addition, she relates these findings to the broader themes of quality education, student diversity, and social inequity.

TITLE: Natural supports in school, at work, and in the community for people with severe disabilities

AUTHOR: Nisbet, J. (Ed.)

PUBLICATION INFORMATION: 1992

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
http://www.pbrookes.com

Promoting the position that assistance must be defined by the needs of individuals rather than the requirements of service systems, this volume includes research and first-person accounts related to use of natural supports. Chapters discuss natural supports in relation to: family issues, school, work, residential supports, social support and friendship, among others. Chapters include practice strategies, stories, and reflection on key issues related to developing and sustaining natural support networks.

TITLE: Designing policies in support of inclusive community: Making questions or decision makers

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1989

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

"People in association create neighborhoods, schools, workplaces, marketplaces, and civic organizations. They build inclusive community when their activity calls on, strengthens, and celebrates mutual capacity to welcome, join with, and care for people who have been left out." But, on the other hand as O'Brien tells us, when activities exclude and isolate people, community is diminished. Based on discussion sponsored with the Connecticut Developmental Disabilities Council, O'Brien poses a series of poignant questions to human service and government decision-makers. Examples of these questions are: "How can we decrease disincentives to participate in community life?" "How can we insure sufficient cash incomes for people with disabilities?" and "How can we invest in activities that build inclusive communities?"

TITLE: Signs of community building

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1989

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

Based on notes he made while visiting with people involved in community building activities in Phoenixville, PA, in this monograph O'Brien discusses the signs of community building that he saw during his visit: "I was struck by the characteristics that these diverse efforts have in common despite their independent origin and their lack of coordination mechanism." He also suggests that community building touches fundamental everyday concerns, including, "to be healthy and to die well," "to have a safe place in times of confusion," and "to reach out to people in other places."

TITLE: Community engagement: A necessary condition for self-determination and individual funding

AUTHOR: O'Brien, J.

PUBLICATION INFORMATION: 1999

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

People with disabilities and their families and friends have a reasonable expectation that people with disabilities will live with security and dignity as contributing members of their communities. Security, dignity, and contribution depend on people, associations, economic actors, and governments each assuming their fair share of the personal and public responsibility necessary to assure the creation and use of accessible opportunities for contribution and the provision of the individualized support and assistance necessary to enable participation. In order to ensure this, it is necessary to implement policies that ensure adequate individual funding, controlled by people with disabilities and their families and friends. At the same time, the author argues that the "urgency and clarity of political action can overshadow the slow and ambiguous work of building wider and deeper relationships with and around people with disabilities and their families."

TITLE: Unlikely alliances: Friendships and people with developmental disabilities

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1993

In A. N. Amado (Ed.), Friendships and community connections between people with and without developmental disabilities (pp. 9-40). Baltimore: Paul H. Brookes Publishing Co.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
http://www.pbrookes.com

Friendships are described as "unlikely alliances" for people who are separated and isolated by prejudice against disability. The authors begin by posing a number of questions: What can people with developmental disabilities expect from their social relationships, particularly their relationships with people without disabilities? Is the meaning of "friend" exhausted by lack of hostility or by benevolent patronage? Or, are some deeper meanings possible, and, if they are, how can people understand them, call them forth, and support them? What challenges come with friendship? The chapter then discusses four dimensions of friendship: attraction, embodiment, power, and community. Through communities of resistance, people can counter the dominant social beliefs that devalue the community's members and their relationships and support one another to get on with their lives.

TITLE: Members of each other: Perspectives on social support for people with severe disabilities

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1992

In J. Nisbet (Ed.), Natural supports in school, at work, and in the community for people with severe disabilities (pp. 17-63). Baltimore: Paul H. Brookes Publishing Co.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
http://www.pbrookes.com

This chapter discusses issues related to community membership and belonging for people with severe disabilities. The authors state, "Because people with severe disabilities cannot take membership for granted, those concerned with building stronger, more inclusive communities must consider how people deny membership can be established." They assert that people with disabilities can teach all of us a good deal about the social relationships that are at the foundation of civil life. Some of these teachings can be categorized into three topics: (1) the consequences of long-term exclusion form common memberships; (2) the benefits implicit in recognition as a member, and (3) some of the explicit work necessary to change patterns of exclusion so that a person moves to being known and treated as a member. Examples are provided of each of these topics. The chapter concludes with discussion of the ways in which human services can help, as well as some of the paradoxes of community building.

TITLE: Unfolding capacity: People with disabilities and their allies building better communities together

AUTHORS: O'Brien, J., & Lyle O'Brien, C.

PUBLICATION INFORMATION: 1994

Lithonia, GA: Responsive Systems Associates.
(Available from the Center on Human Policy)

This paper discusses efforts to build community, based on what the authors have learned by listening to stories of people who have worked together to make important changes in their lives. These changes, all involving people with significant disabilities, include such things as: establishing adequate support for family life; moving from an institution, medical hospital, nursing home, or group residence into one's own home; moving from one's family's home to a home of one's own; getting a job in an ordinary community workplace; and attending school as a member of ordinary classes.
As the authors' see it, "community building happens when people step outside the roles prescribed by the formal and informal administrative structures and the assumptions that typically organize life for people with substantial disabilities" (p. 6). They describe five commitments that contribute to building community: anchor, allies, assistance, agendas, and associations. Each is discussed briefly. The paper concludes by addressing issues related to the importance of community building and tensions in community building.

TITLE: The gift of hospitality: Opening the doors of community life to people with disabilities

AUTHOR: O'Connell, M.

PUBLICATION INFORMATION: 1988

Institute for Policy Research
Northwestern University
2040 Sheridan Road
Evanston, IL 60208
847-491-8712 fax: 847-491-9916
http://www.northwestern.edu/IPR/index.html

This monograph is part of the growing literature that critiques the human service system even when it is based in the community. It describes the efforts of people with a

variety of disabilities to take their place within the community and by others to accept them. O'Connell asserts that community-based services can isolate people with disabilities from community life. Surrounded by paid staff, many clients in the human service system are cut off from the opportunities to meet and develop relationships with typical people.

By sharing the experiences of individuals with disabilities who have been welcomed into the hearts and lives of others, O'Connell introduces a practical definition of hospitality. She suggests that hospitality is "...the fundamental sense that you have to appeal to in asking other people to get involved in this work of welcoming isolated people back into the community." For the author, achieving the fullest possible integration of individuals with disabilities into society involves acts of welcome and hospitality by those who are already members.

This monograph would be useful reading for those interested in the meanings of "community integration" for people with disabilities.

TITLE: Making friends: Developing relationships between people with disabilities and other members of the community

AUTHOR: G. Allan Roeher Institute

PUBLICATION INFORMATION: 1990

The G. Allan Roeher Institute
Kinsmen Building, York University
4700 Keele Street
North York, ON M3J 1P3
CANADA
416-661-9611 TDD 416-661-2023 fax 416-661-5701
info@roeher.ca
http://www.roeher.ca

This book examines many critical issues related to friendships. It looks at how the presence or lack of friends and other relationships affects people's lives. It also explores key elements of friendship, examines conditions that support the development of relationships, identifies key barriers that need to be overcome, and outlines practical options that can be pursued by those concerned with promoting friendships and other relationships.

TITLE: Crossing the river: Creating a conceptual revolution in community & disability

AUTHOR: Schwartz, D. B.

PUBLICATION INFORMATION: 1992

Brookline Books
P.O. Box 1047
Cambridge, MA 02238
1-800-666-2665 or 617-868-0360
BROOKLINEBKS@delphi.com
http://people.delphi.com/brooklinebks/index.html

As increasing numbers of people with developmental disabilities have been assisted to live in community-based settings, at the same time, the community services system has failed, in many ways, to help people become participants and members of the community. The conceptual revolution that Schwartz describes involves "rediscovering the importance for all people of being and feeling embedded in a web of personal relationships."

The book begins with two chapters describing efforts to assist people to form community connections (a chapter on connecting people to community associations, by Sharon Gretz; and a chapter on citizen advocacy in Beaver County, Pennsylvania, by A.J. Hildebrand). Following chapters discuss the idea and process of conceptual revolutions, and describe the efforts of the Pennsylvania State Developmental Disabilities Planning Council to foster and support conceptual change. The book concludes with a discussion of issues regarding what keeps people safe, the limitations of community, the role of human services, and the challenges to building community.

TITLE: A story that I heard

AUTHORS: Schwartz, D. B., McKnight, J., & Kendrick, M.

PUBLICATION INFORMATION: 1987

Pennsylvania Developmental Disabilities Council
Room 559, Forum Building
Commonwealth Avenue
Harrisburg, PA 17120
717-787-6057
info@paddc.org
http://www.paddc.org/

This monograph is a collection of stories, poetry, and essays about the situation of people with disabilities in American communities. It includes writing by people who have disabilities, family members, and friends and advocates.

TITLE: Social integration and friendship

AUTHORS: Strully, J. L., & Bartholomew-Lorimer, K.

PUBLICATION INFORMATION: 1988

In S. M. Pueschel (Ed.), The young person with Down syndrome: Transition from adolescence to adulthood. Baltimore: Paul H. Brookes.

Paul H. Brookes Publishing Co.
P.O. Box 10624
Baltimore, MD 21285-0624
1-800-638-3775 fax 410-337-8539
custserv@pbrookes.com
http://www.pbrookes.com

In the first part of this chapter, Strully and Bartholomew-Lorimer neatly summarize the experiences of many people with disabilities at the hands of the human service system. By receiving services, individuals are turned into clients and become viewed primarily in terms of their particular disability. They are surrounded by programs and staff, and are cut off from typical people, places and events. One result of this is that people in the community come to believe that segregation is an appropriate response to people with disabilities.

The authors propose that freely given friendships between typical and disabled people "...are at the root of developing competent, caring communities for us all." They then present two case studies illustrating how to enable a person with disabilities to develop such friendships and the impact of these relationships for the people involved.

TITLE: Friendship and our children

AUTHORS: Strully, J., & Strully, C.

PUBLICATION INFORMATION: 1985

Journal of The Association for Persons with Severe Handicaps, 10(4). 224-227.

The close and caring relationship between two people known as a friendship requires shared experiences in order to develop and grow, and children who go to school together have the opportunity to develop relationships as well as skills. This essay about the friendship between Shawntell and Tanya, who attend intermediate school together, raises an important question: No matter what a school program has to offer, if it prevents children like Tanya and Shawntell from sharing daily experiences and becoming friends, is "special" good enough?

TITLE: On accepting relationships between people with mental retardation and non-disabled people: Towards an understanding of acceptance.

AUTHORS: Taylor, S.J., & Bogdan, R.

PUBLICATION INFORMATION: 1989

Disability, Handicap & Society, 4(1), 21-36.

This article outlines the "sociology of acceptance" as a theoretical framework for understanding relationships between people with mental retardation and typical people. As a point of departure, the authors review sociocultural perspectives on deviance and explore their contribution to the study of mental retardation. Based on qualitative research on community programs for people with severe disabilities, the authors next examine the nature of accepting relationships and describe four sentiments expressed by typical people who form relationships with people with mental retardation: family, religious commitment, humanitarian sentiments, and feelings of friendship. The article concludes with a brief discussion of the sociology of acceptance for the field of mental retardation.

TITLE: From community presence to sense of place: Community experiences of adults with developmental disabilities

AUTHOR: Walker, P.

PUBLICATION INFORMATION: 1999

JASH, 24(1), 23-32.

The places where people spend time and the experiences they have in these places are critical to the development of a sense of place and community connections. This study, based on individual experiences, reveals that adults with developmental disabilities commonly spend time in laces designated for people with disabilities versus the general public, in public versus private places, and in places characterized by business transactions versus social interactions. Within the community, the research participants have a variety of experiences. They range from a sense of vulnerability to a sense of safety, a feeling of being socially anonymous or isolated to a feeling of being known, from disaffiliation to identification, from unfamiliarity to familiarity, from a sense of being rejected to a sense of being liked or accepted, and from a sense of unwillingness/willingness to provide accommodations. The article concludes with strategies that service providers and others can use to increase opportunities for positive community experiences and sense of place.

U.S. Department of Education
Office of Educational Research and Improvement (OERI)
National Library of Education (NLE)
Educational Resources Information Center (ERIC)

NOTICE

Reproduction Basis

[X] This document is covered by a signed "Reproduction Release (Blanket)" form (on file within the ERIC system), encompassing all or classes of documents from its source organization and, therefore, does not require a "Specific Document" Release form.

[ ] This document is Federally-funded, or carries its own permission to reproduce, or is otherwise in the public domain and, therefore, may be reproduced by ERIC without a signed Reproduction Release form (either "Specific Document" or "Blanket").